Training choice-making behaviours of adults with intellectual disabilities

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STATEMENT

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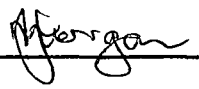
Signed: 

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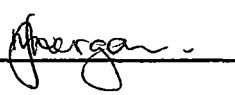
Signed: 

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ABSTRACT

This thesis examines the daily choice-making behaviours of adults with intellectual disabilities in order to develop a training program for improving these behaviours following the three-stage model of choice developed by Zilber, Rawlings and Shaddock (1994).

It begins with the development of the Daily Choice Questionnaire (DCQ), which quantifies choice behaviours in each of the three stages: Option Recognition, Evaluation and Selection, and Acting on the Selection. This instrument was used to assess the impact of resident, environmental, and support worker characteristics on the expression of the choice behaviours of 43 adults with intellectual disabilities living in 11 group homes. This analysis indicated that resident characteristics, particularly measures of ability, most influenced choice behaviours.

The DCQ was then used to evaluate a number of approaches for training choice-making. These involved intervention with either the resident (skills training), the support worker (opportunity training), or both. Involving the same participants as the previous study, the combined approach proved to be the most effective, both in increasing the frequency of opportunities and follow-through of choices. Although there were few other effects on choice behaviours, some of the negative effects of using opportunity or skills training in isolation were apparently prevented by the combined use of both forms of training.

In the last two studies, 79 residential support workers rated 59 group home residents on their availability of choice in 16 daily choice areas. These ratings were used to develop a model of choice availability that describes the relationships between resident disability, support worker attitudes to the choice skills of residents, and choice availability. One of the key implications of this model is that choice availability is a consequence of both general resident ability, and support worker perceptions of the development and teachability of choice skills. This finding reinforces the need to train both the resident and the support worker in order to influence the availability of choice.

Resident choice availability ratings were then compared to similar ratings for 198 individuals without an intellectual disability. These individuals ranged in age between four months and 56 years, and lived in family homes of between three and five people. Equations were developed to predict the age-equivalent choice availability as a function of the level of disability. These can be used to set goals for increased choice availability consistent with normalisation.

The thesis concludes with a discussion of the implications of the findings for further refinement of a combined opportunity and skills training approach to improve the choice behaviours of adults with an intellectual disability.

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Chapter One

INTRODUCTION

The traditional medical model of human services defines individuals with severe disabilities as sick or disordered and in need of treatment (Olney & Salomone, 1992). However, there have been dramatic shifts in broad public policy regarding the provision of programmes and services to people with an intellectual disability in Australia, as in much of the Western World. These services have tended to be based on the values and philosophies of the society at the time rather than on well established, unequivocal, reliable and valid research findings (Parmenter, 1990).

The current climate of resident choice and decision-making is founded primarily on the principles of normalisation (Chapter Two). However these are not empirically established fact, but rather heavily value-laden principles of human justice and human rights (Parmenter, 1990). Deinstitutionalisation, moving people with an intellectual disability from large institutions into smaller community residences (Chapter Three), is the dominant strategy used to achieve normalisation. Yet research has shown that this strategy is not always successful in achieving more normalised environments (Brown, 1988).

In order to identify and provide the best and most appropriate services for people with an intellectual disability, Parmenter (1990) stressed the need for more intensive research efforts in these areas. In particular, he posed the question "What strategies are needed to develop informed decision-making and choice among people with intellectual disability?", as even when these are agreed to be worthwhile goals (Chapter Four), the problem of how best to achieve them remains (Chapter Five).

The primary goal of this thesis is to take up this question and explore how to achieve an increase in the choice-making of people with an intellectual disability. The examination of the choice-making of adults with

an intellectual disability will begin with the design of a method of assessing choice (Chapter Seven). This will be used to investigate the expression of various aspects of choice, and the impact on these of a range of characteristics of the individual with an intellectual disability, their support workers, and the environments in which they live to (Chapter Eight). This will be followed by an evaluation of a number of training strategies for improving choices involving residents or support workers (Chapter Nine). The final two studies further explore the impact of support worker perceptions of choice availability (Chapter Ten), and compare the frequency of choices available to those with and without a disability (Chapter Eleven). The thesis finishes with an examination of the impact of the findings on the further development of training to improve various aspects of resident and support worker behaviour with relation to choice-making.

However, before beginning the investigation it is important to clearly identify the population of interest, and outline some of the theoretical and practical considerations for the development of training in choice-making for this population.

INTELLECTUAL DISABILITY

Intellectual disability essentially involves inefficient cognitive functioning but encompasses enormous individual differences. Disability may also be the result of a developmental lag so that the individual is distinguished from peers without a disability by the rate, rather than the quality of their mental development. For a large majority of people their intellectual disability does not have a detectable physical basis, and psycho-social factors play an essential causative role. Thus, it is both individual characteristics and environmental factors which affect the expression of any deficits and influence the functional level of any disability (Hull & Thompson, 1981).

The labels used to describe and define people with an intellectual disability play a significant part both in the way that they view themselves and also in the way the community perceives them. This can have

benefits as it provides a neat diagnosis and promotes appropriate treatment through facilitating effective communication and serving a gate-keeping function for provision of specialised services. However, labels can also be laden with connotations that promote bias and alter the perceptions of people toward the individual despite the lack of behavioural evidence to warrant the perceptions. This has been noted in teacher's lowered perceptions of their student's self-determination for those labelled as disabled even though there was little difference in the observed behaviours of these students (Field, Hoffman, St. Peter & Sawilowsky, 1992).

Many different terms have been used to label people with an intellectual disability such as *mental deficiency*, *mental handicap*, *mental subnormality*, *educationally subnormal*, *mental retardation*, *intellectual handicap*, and *feeble minded*. Some have extremely negative connotations and have been used to reinforce perceptions of deviancy. This can result in rejection by family, friends, human service workers, and others, increasing the likelihood that a person will experience discontinuity in social relationships and physical surroundings. The resulting long-term psychological trauma can compound an individual's disability even further.

One of the problems with terminology is that 'disabled' and 'handicap' are not equivalent terms as two people with equivalent impairments are not necessarily handicapped to the same degree. 'Disability' is the restriction or lack of ability to perform a particular activity, while the 'handicap' experienced is further influenced by educational and social factors (Heron & Myers, 1983). For this reason 'disability' appears to be the more appropriate term, and to avoid confusion with mental health, association with the word 'mental' will be avoided. Currently, the most widely accepted term is "people with an intellectual disability" as this reinforces that the individual is a person first, who happens to have an intellectual disability second.

Definition

It is extremely difficult to arrive at a consensus definition of '*intellectual disability*' as this term has been used to refer to people of

widely varying ability. Even when the focus is on the range known as severe intellectual disability, Parmenter (1990) outlined four possible ways that disability could be defined. These are: the *intellectual* approach using the IQ range between 20 and 35 (an IQ of less than 70 is believed to indicate an intellectual disability generally); the *functional* approach, which determines the person's lack of competencies; the *service requirement* approach, which defines a person as having a severe intellectual disability if they require a large number of services; and the *previous service* approach, which classifies a person as having a severe intellectual disability if they have previously attended a service catering for the needs of those with severe intellectual disabilities.

All these definitions have problems. Intelligence Quotient scores are notoriously unreliable at the extreme ends of the range, and tests are usually not appropriately meaned for those considered disabled. The second definition does not specify which basic functions should be assessed or how. The third does not answer the question of how many is "a large number of services" and the fourth definition fails to explain how previous services defined intellectual disability. Much of the problem with the definition of severe intellectual disabilities is with the term "severe" as it is difficult to specify and covers such a wide range of people with a variety of characteristics and handicaps. Sometimes it simply refers to people who fall in the "too hard basket" and can lead to the problem of people being considered *too* severe to be catered for.

The Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV) (1994, page 40) still uses the term Mental Retardation and defines it as:

- significantly subaverage intellectual functioning,
- concurrent deficits or impairments in present adaptive functioning in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-education, functional academic skills, work, leisure, health, and safety; and
- onset before age 18 years.

It also makes use of IQ to determine the severity:

Mild – IQ of 50-55 to approximately 70,

Moderate – IQ of 35-40 to 50-55,

Severe – IQ of 20-25 to 35-40, and

Profound – IQ of less than 20 or 25.

These categories are based on standard deviations in IQ score from the mean (IQ of 100). Mild intellectual disability is defined as two standard deviations, moderate is three, severe is four, and profound is five standard deviations below the norm. In the past there was also a category known as 'borderline' which was one standard deviation below the norm (IQ ~70-85) but it is generally agreed that this group does not have an intellectual disability although they may be considered 'slow' when compared to the norm.

Although different tests of intelligence have different standard deviations, the use of approximate IQ ranges indicates the inaccuracy of this method of definition. The use of bands rather than sharp cut off points can also be used to allow sound clinical judgement to partially determine the existence of, and level of, intellectual disability.

Another definition focuses on ability to learn and uses '*educational categories*'. In the above definitions, *mild* mental retardation is roughly equivalent to the category referred to as "educable", while *moderate* is equivalent to the "trainable" category. Again, these categories are poorly defined regarding *what* the individual is capable of being educated or trained in.

The definition adopted by the report of the Joint Commonwealth and State Review into the needs of people with an intellectual disability in Tasmania (1984), was that developed by the American Association on Mental Deficiency (1973):

"Intellectually handicapped (disabled) people are those with statistically significant sub-average general intellectual functioning which exists concurrently with deficits in adaptive behaviour and which is manifested during the developmental period".

Intelligence may be considered the ability to acquire, remember, and use information appropriately. People with an intellectual disability do not learn as effectively or efficiently as others. Reduced learning and

memory capabilities make it harder for these individuals to grasp the abstract, generalise to new situations, and focus on relevant stimuli.

The inclusion of adaptive behaviour in the above definition enables adaptive behaviour to be considered of equal importance to subnormal intellectual functioning in determining intellectual disability. This enables a degree of compensation for the lack of agreement regarding a definition of intelligence and what factors intelligence tests measure, the cultural bias of many intelligence tests, and any error involved in testing. Furthermore, intelligence tests measure the average range of abilities and do not easily account for individuals who may have quite high scores in some areas and low scores in others.

Adaptive functioning is the capability of individuals to take care of themselves and to relate to others around them. Impairments in adaptive behaviour are considered to be significant limitations in a person's ability to meet standards of maturation, learning, personal independence, and social responsibility that would be expected of another individual or comparable age level and cultural group. These are usually measured using adaptive behaviour scales based on structured interviews or direct observation. The classifications for adaptive behaviour tend to be descriptive in nature and are based on maturation, learning, and social adjustment (Ehlers, Krishef & Prothero, 1973).

The third component of the American Association on Mental Deficiency (1973) definition is developmental period. This usually refers to the period prior to the eighteenth birthday. The inclusion of developmental period in the definition helps to distinguish those with an intellectual disability and those with problems that originate in the adult years such as head injuries or strokes.

This thesis will not tackle the problem of defining intellectual disability but, like the above definition, will account for both adaptive behaviour and intellectual functioning. Level of intellectual disability is rated by both the house manager and the support workers. The rating given by the house manager or service provider is expected to be at least partially based on more objective measures, such as IQ tests, which are

used to determine funding levels for individual residents. The rating based on the support workers' perceptions of the people with intellectual disabilities is likely to be relative to the other people with disabilities that the support worker is familiar with.

The abilities of the individual rather than just their disability will be accounted for using an adaptive behaviour assessment, the Scales of Independent Behaviour (Bruininks, Woodcock, Weatherman & Hill, 1985) and an assessment of communication skills, the Communication Assessment Profile for Adults with a Mental Handicap (CASP - Van der Gaag, 1988).

LOCAL POLICY

Policy in Australia has followed similar directions to that of the remainder of the Western World. Since the 1970's, many government-sponsored reports into services for people with developmental disabilities in Australia have recommended relocation of clients from hospitals into community houses, and some have even recommended the closure of institutions (Molony & Taplin, 1988). This has led, in relatively recent times, to a policy of deinstitutionalisation and moving people with an intellectual disability out into the community.

In Tasmania, this policy has resulted in the Community Integration Project and this has led to the gradual reduction of the population of Willow Court Centre, Tasmania's only residential institution for people with intellectual disabilities. For many years, Willow Court catered for adults with a range of intellectual and other disabilities and provided leisure, habilitation, and employment services on site. One option for residents of Willow Court is accommodation in community based group homes, usually housing between three and six people. These houses are managed by residential support services, which receive government funding to provide staffing according to the level of support required by each individual.

The Community Integration Project is also based on the principles of normalisation and services are provided according to a set of standards. Disability Service Standard number three specifies that: *"Each person*

with a disability has the opportunity to participate as fully as possible in making decisions about the events and activities of his or her daily life in relation to the services he or she receives."

Furthermore, the position description for the Welfare and Voluntary Workers Award (WAVA) that covers support workers in residential settings reads:

d. Communication

I. Communicate with residents using recommended procedures whilst encouraging resident choices and decision-making.

Unfortunately, despite the best of intentions, practice does not always keep up with policy. Although many support workers recognise that it is part of their role to encourage choice and provide opportunities for the expression of choice they are not sure exactly how to go about this. In 1988, the Association for Persons with Severe Handicaps affirmed the right of persons with severe handicaps to freedom of choice in all types of settings. They also resolved that families and professionals should systematically work toward the development of real opportunities and programmes for choice, and that people be encouraged and supported to make choices through exposure, awareness, interaction and instructional opportunities.

INCREASING CHOICE

Current policy directions challenge the perceived dependency and deviancy of people with an intellectual disability. The focus is now on the rights and capabilities of all people to make decisions for themselves or to learn to do so. However, real choice-making still tends to be limited for people with intellectual disabilities (Cullen, 1999). Clearer guidelines and training programmes are needed to assist people with intellectual disabilities to develop choice-making skills and overcome lack of experience with choice-making in the past. Achieving increased choice-making can be approached from a number of angles: either directly by teaching the individual, or indirectly by altering the environment (Stancliffe, 1991). The environment consists of more than just physical structures, but

also the social supports and attitudes of others. In the case of people with an intellectual disability this primarily involves the support workers.

Individual Focus

In order to maximise potential, it is important to emphasise the capabilities rather than the disabilities of an individual. A sense of accomplishment can have a significant impact on an individual's perception of control, and can stimulate learning through challenging boundaries. Individual differences must be taken into consideration in order to work within the person's capabilities, and support should be provided only to the degree needed to encourage full use and development of skills in order to maximise potential. Maximum independence is the goal but this can often only be achieved through support. Although interdependence is considered by far preferable to dependence or isolation, wherever possible people with an intellectual disability should be seen as taking the major role in decisions rather than simply being an equal member of a team (Jenkinson, 1993).

Environmental Focus

Increasing independence involves more than just teaching people with an intellectual disability to be more involved in daily-living tasks. Programmes also need to consider the environment as aspects of the environment frequently underlie or maintain existing behaviours (Cullari & Ferguson, 1981). Therefore, to ensure that changes can be supported, encouraged and maintained, it is important to address the physical and social environment in which the individual lives. The physical environment needs to be accessible, and resources, such as funding for support workers, needs to be available. Programmes need to be carefully planned to avoid exploitation or neglect through inadequate community resources.

The social environment may also need to be addressed through strengthening the bonds between those with and without a disability. This can result in increased opportunities for skill development and image enhancement. Community perceptions of deviance can be altered

through positive interactions with people with disabilities who display competencies in ordinary community settings.

Support Worker Focus

Another important aspect of the social environment is the interactions between residents and support workers. Support workers need to be trained to be creative and flexible. Every resident, and each new situation, requires a fresh approach in order to determine how the needs for intervention and support can be balanced with the need for the individual to exercise control and choice. Promoting self-sufficiency and heightened self-esteem requires support workers to identify real choice and empower individuals to take charge of their own lives, and actively support their self-direction and decision-making.

DAILY CHOICES

Although Stancliffe (1991) stated that many people with an intellectual disability have the capacity to be involved in a wide range of decisions, the focus of this thesis is on daily choice-making activities. There are both theoretical and practical reasons for this. Firstly, training in day-to-day choices is expected to lay the foundation for making choices about major issues in the future. Secondly, by definition, daily choice-making occurs more frequently. This provides numerous opportunities for practicing choice-making skills during training, and repeated examples of choice-making which can be assessed to measure the effectiveness of training.

The selection of daily choice-making as the focus for the present training and evaluation also led to a focus on residential settings as this was where most daily choices were expected to take place. Furthermore, as choice has been found to differ in different types of settings (Shaddock, Zilber, Guggenheimer, Dowse, Bennett & Browne, 1993), one type of residential setting was selected for investigation of daily choice-making in this thesis. As policy in Tasmania has led to the predominance of shared accommodation in community houses, group homes were selected as the most appropriate residential setting to examine at this time.

TERMINOLOGY

As a result of the focus on daily choices in group home settings, people with an intellectual disability will also be referred to as *residents*. Furthermore, to emphasise the importance of the supportive, rather than caring role of the staff in residential settings, staff will be referred to as *support workers* in this thesis.

SUMMARY

In recent years the principles of normalisation have had wide-reaching implications for the provision of services for people with an intellectual disability. One of the consequences is an emphasis on resident decision-making and choice. However, normalisation is based on the values and philosophies of today's society, and relatively little research has been carried out into the value of these principles, or how to achieve increased decision-making or choice.

As with the Advancing Choice Project (Bennett, 1991) headed by Professor Tony Shaddock of the University of Canberra, the theoretical development of this thesis is founded on values such as normalisation, individual rights, and empowerment. The thesis is also founded on the importance of services being based on research. It begins by examining the impact of the concepts of normalisation and deinstitutionalisation on the availability of daily choice, and the impact of daily choice-making, or its absence, on the lives of people with intellectual disabilities. This is followed by a series of studies which address four key questions: how can choice be measured, what influences choice, can training improve choice, and do the choices of those with a disability differ from those without? The conclusions of these studies are then used to propose a refined choice training programme.

Chapter Two

NORMALISATION

The current emphasis on human rights and resident choice, has resulted in the set of attitudes embodied in the concept of normalisation. This in turn has been widely adopted to guide the planning and provision of services to people with an intellectual disability (Anstey & Gaskin, 1985). Normalisation is an ideology in human services based on the proposition that quality of life increases as access to culturally typical activities and settings increases (Landesman & Butterfield, 1987).

There are widely discrepant viewpoints about the normalisation concept, and this has led to some lack of support for the approach (Anstey & Gaskin, 1985). The main viewpoints are based on Nirje's concept of *normalisation* and Wolfensberger's concept of *social role valorisation*. The differences between the concepts have repercussions for the choices available to people with an intellectual disability.

NIRJE'S NORMALISATION

According to its original formulation by Nirje (1973), *normalisation* means "making available to all intellectually disabled people patterns of life and conditions of every day living which are as close as possible to the regular circumstances and ways of life of society." This implies primary stress on means and methods rather than outcome (Wolfensberger, 1980). Nirje believed that normal patterns and conditions of life involve both structural and social conditions as these have inherent value through the enhancement of an individual's experience and control.

Normalisation does <u>not</u> mean making people with an intellectual disability 'normal'. People are not expected, or forced, to act as if normal or to conform in all respects to society's statistical norms for all dimensions of behaviour. It is about providing opportunities and support to permit a lifestyle similar in nature to that of other members of society including similar opportunities for individual variation and, most importantly, choice.

In essence, it is the acceptance of the person, and their disability, with the same rights and responsibilities as any other member of society.

Providing normal conditions of life to people with intellectual disabilities has value in itself as well as the desirable outcome of improving the quality of self-perception. Identity is defined by the circumstances and conditions of our existence; therefore normalised conditions can help promote the experience of self as an emotionally alive and physically active person with valid desires and choices. Normal life conditions include both normal structural conditions such as physical facilities and temporal rhythms as well as normal social conditions including normal economic security and contact with the opposite sex. Above all, these conditions incorporate flexibility and freedom of choice.

The normalisation principle is a humanitarian principle that demands the standards the general community takes for granted and can be applied in an institutional setting, as well as in the community, utilising whatever finances and resources are available. The philosophy of normalisation is humanising, quality enhancing and appropriate but only if the necessary resources and personnel are made available (Brown, 1987). Educational, developmental, and vocational services need to be available to prepare the individual for integration into normal community modes of living, school, training, work, and social outlets. However, support services should be provided only to the degree they are needed so that full use of skills and potential can be achieved (Menolascino & Eaton, 1980).

Normalisation is not an all or nothing concept and nor does physical placement in the community necessarily represent normalisation or integration. There are degrees of normalisation (Perrin & Nirje, 1985) and the principle implies the provision of a range of structures and supports depending on the individual's needs and abilities. Normalisation may be a gradual process which enables the individual to live as normal and independent a life as their present skill development allows, with gradual reduction of supports as skills develop. Special services are not inconsistent with the normalisation principle (Perrin & Nirje, 1985) as anyone faced by an unfamiliar situation may require assistance. Rather,

the normalisation principle insists on the provision of whatever services, training and support are required to permit living conditions and routines similar to those of others in the community. Normalisation is therefore appropriate for any degree of disability, and its implications may be the most far reaching for those with more severe disabilities (Perrin & Nirje, 1985).

Although people tend to agree on the general aspects of normalisation, they disagree on the amount of control and protection that should be exercised. For Nirje, the means through which normalisation is achieved have as much value as the final goal of social integration of people with disabilities into the general community. In his definition, Nirje refers only to normalising environmental conditions, Wolfensberger however, emphasises normalising the *behaviour* of the person with a disability as well as their *environment.*

WOLFENSBERGER'S SOCIAL ROLE VALORISATION

Wolfensberger expanded the concept of normalisation in 1980 into a complex ideology that has led to confusion and the view that it refers to normalising the person rather than the environment. To Wolfensberger (1983), normalisation involves the enhancement of social image and the improvement of social competencies of devalued people. The goal is to reduce the perceived deviancy of people with an intellectual disability primarily through the elimination of their unacceptable or inappropriate behaviours. He thus defines normalisation as "utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible". Thus Wolfensberger (1980) intended his concept to encompass both means and outcomes. This suggests that it is not sufficient to use normalised methods of intervention; one must also demonstrate that these methods lead to normalised behaviours as an outcome (Neisworth & Smith, 1978).

As the original idea of normalisation came out of Scandinavia, Wolfensberger's intention was also to adapt the concept for service

delivery in North America. In 1983 Wolfensberger suggested the term *'social role valorisation'* to describe his reconceptualisation of Nirje's normalisation. His aim was to develop a tightly built, intellectually demanding, and empirically well-anchored mega-theory of human service. Wolfensberger believes that the highest priority of social role valorisation is to create, support, and defend valued social roles for people at risk of social devaluation (Brown, 1987). This, he feels, will lead almost automatically to other desirable things being accorded to the person within the resources and norms of the society in which the individual lives.

Devaluation

How an individual is perceived has repercussions for how they are treated and consequently how they behave. A person who is considered devalued will tend to be rejected, persecuted, and treated badly; and due to a tendency to conform to expectations, the person may then act in unacceptable or inappropriate ways. This behaviour will reinforce the perceived deviance and the cycle is perpetuated. However, if the stigmata are reduced or prevented, then societal perceptions of the devalued person may change so that they are no longer seen as devalued. This can be achieved through the enhancement of social image and social competencies.

Social and cultural norms determine how a person is perceived and treated by others, and the devalued characteristics of some cultures are valued in others. Hallucinations are an example of this, they are seen as the sign of a gift in some cultures, while in others they are seen as a sign of madness. People with an intellectual disability have been perceived in different ways by different societies. They have been feared, ridiculed, pitied, and revered. In the Greek city-state of Sparta where prowess in warfare dictated physical fitness and educated citizens, the physically or mentally unfit were subject to infanticide or child murder. However in Roman times certain wealthy citizens kept some of the dull for amusement, and the use of those with disabilities as jesters or fools persisted into medieval times (Cleland & Swartz, 1982). Demonology, or the belief that those with a mental disability or illness were possessed of

evil spirits also prevailed in medieval times and 'cures' often involved exorcism or beatings.

Historically, in western cultures, the devalued image of people with intellectual disabilities has been reinforced rather than reduced by drawing attention to the differences between them and the general community (Wolfensberger, 1978). This both led to, and was a consequence of, grouping people with an intellectual disability in institutions. Interaction with the general community was further reduced by frequently locating these institutions away from the rest of society, in locations with poor transportation (McCord, 1982). The result was fragmentation of the life of the person with a disability due to separation from family and friends and increased experience of discontinuity in social relationships and physical surroundings. The devalued image has been further emphasised by building the institutions on or near a site used by some other devalued group, such as a former brothel or tuberculosis sanatorium, or condemned as unfit for human use, such as on a garbage dump or cemetery. Other means of devaluation include constructing an institution that is so large that people cannot be related to as individuals; mixing devalued client groups and age groups; using ridiculous or stigmatising names; and employing stigmatised or devalued staff.

Image Enhancement

According to social role valorisation, the community is most likely to alter their perceptions of deviance through positive interactions with people with a disability who display competencies in ordinary community settings. One of the goals of social role valorisation (McCord, 1982) is to strengthen the bonds between devalued people and their communities through closer proximity and positive interactions that reveal competence. Wolfensberger also believed that it is not enough merely to present people who have been socially devalued in a statistically normative way, but rather they should be presented at the highly valued end of the continuum. This came to be known as the conservatism corollary.

Another focus is on enhancing competence through the development of skills including those involved in choice-making. Skills are

most appropriately and efficiently learnt in settings that demand knowledge of those skills through positive role modelling and an informal, one-to-one teaching process. Skill development and image enhancement are closely interrelated as success in one often leads to improvement in the other.

CRITICISMS OF NORMALISATION

Cultural Bias

One of the criticisms of normalisation is that it is purely a Scandinavian concept that is not applicable elsewhere (Perrin, 1982). However, Nirje's emphasis on normal living opportunities, patterns, and circumstances of life is neutral regarding cultural values, even though the definition of 'normal' is culturally specific. What constitutes normal living patterns and opportunities will vary from society to society. What is important in the implementation of the principles of normalisation is that people with an intellectual disability have opportunities similar to those of other members of the community in which they live, including opportunities for choice.

People Changing

The principle of normalisation is sometimes viewed as a people changing intervention that attempts to make people with disabilities normal. Intellectual disability has traditionally been perceived as a pathological condition manifested by biological and behavioural symptoms that are most effectively remedied by a medically oriented approach. This results in a preoccupation with the aetiology, prevention, and care of intellectual disability in a similar way to that for a disease (McCord, 1982). This has resulted in approaches that place a high priority on eliminating disabling conditions but with no understanding of the relationship between the needs of a person with a disability and the prevailing values and norms of society. Some see normalisation as a passive attempt to 'cure' people with disabilities by relating to them as if they do not have any special needs. This is not the approach that Nirje advocated in his concept of

normalisation. According to Nirje, normalisation is about providing normal opportunities and the support to take advantage of those opportunities. The individual retains the choice of whether or not to take up the opportunity.

Damage to Image

A criticism of Nirje's formulation of normalisation by advocates of social role valorisation is that too much freedom to exhibit deviant behaviour will add to the perception of people with an intellectual disability as devalued. From Nirje's point of view though, social role valorisation is not worth pursuing if it requires rejection of an individual's right to expression of choice. Nirje's version of the concept allows people with an intellectual disability the right to engage in unpopular, nonconformist and even deviant behaviour as does the rest of the community (Perrin & Nirje, 1985). Normalisation is thus humanistic, egalitarian and emphasises freedom of choice and the right to self-determination. The emphasis is on respect for the individual and the right to choose, even to be different.

CRITICISMS OF SOCIAL ROLE VALORISATION

Lack of Individuality

One of the major criticisms of social role valorisation is that it does not allow for individual choice. Wolfensberger focused on establishing normative behaviour and his approach is based on a fundamentally different value base and conception of people from Nirje's normalisation with quite different implications for the treatment of people with a disability.

In the conservatism corollary Wolfensberger specifies standards of behaviour that must be conformed to. These standards are typically equated with white, middle class values, rather than recognising the heterogeneity of the community and the values that they hold (Bleasdale, 1994).

People are then normalised through eliciting, shaping, and maintaining normative skills and habits even if this requires the use of force (Perrin & Nirje, 1985). Social role valorisation makes little provision

for personal preferences and although Wolfensberger's approach does not oppose self-determination he indicates that when choice conflicts with behaviour that is defined as appropriate and normalised, the latter should take priority. Individual feelings or reactions are considered irrelevant in this context. Wolfensberger's approach requires conformity to values chosen by others and is seen by some as an unwarranted abuse of power. Some feel that social role valorisation is excessively concerned with the notion of people with intellectual disabilities "passing" in society and requires them to avoid doing anything which would make them stand out or attract attention. From this perspective, the focus is on the appearance, rather than the reality of normalisation, at the cost of subjective satisfaction and choice (Perrin & Nirje, 1985).

Rejection of Disability

Social role valorisation is also criticised for focussing so much on the prevention of appearing devalued that it denies the individual's disability (Perrin & Nirje, 1985). Acknowledgment of the disability can allow a more realistic self-appraisal in terms of what the individual can or cannot do. This enables more realistic goal setting, better coping strategies, and reduces the tendency to avoid challenges in order to ward off inevitable failure. People with an intellectual disability who repeatedly experience failure may artificially limit their horizons in order to avoid failure.

Open discussion and realistic ideals can result in a more objective assessment of strengths and weaknesses, and correlate with good self-acceptance. When disability is a taboo subject, it can lead to an individual feeling lonely, isolated, and abnormal, and aware of being treated differently in a way incompatible with 'normal' status. However, continually being seen as devalued may also contribute to a sense of failure, and advocates of social role valorisation suggest that this can be prevented by promoting socially valued behaviour.

Responsibility for Change

A further criticism of social role valorisation is that it places all responsibility for change on the person with the disability and does not attempt to change the cultural views that lead to people with a disability being viewed as devalued (Bleasdale, 1994). Deviancy is not determined by the nature of the person or the deviant act itself, but by the community's interpretation of that person or act. For people with an intellectual disability it is the perception of deviancy by the community that negatively differentiates them from the rest of the community.

Ideally, normalisation should involve reform of language and the redefinition of the term 'normal'. This definition varies even between the two versions of normalisation. In Nirje's conceptualisation, the word 'normal' means usual, typical, or conventional, while according to Wolfensberger it means behaviour that is acceptable and appropriate. It is important to recognise that norms are determined by attitudes towards behaviour not the behaviour itself. Furthermore, social role valorisation appears to promote dual standards regarding behaviour that is acceptable from the general community, and what is acceptable from people with an intellectual disability.

Focussing on the powerless group is easier than attempting to educate the public and remove the stigma of disability. Some of the impetus for destigmatising the social role of people with a disability must come from the community. This can be achieve through the provision of environments and opportunities that enable people with intellectual disabilities to demonstrate their ability to take control of their lives. This requires the normalisation of society's attitudes toward people with an intellectual disability through reduction of prejudice, better human relations and improved understanding (Briton, 1979).

Prevention of Association with Devalued Groups

Another of the criticisms of social role valorisation is that there is such an emphasis on outward appearance that identifying with other people with an intellectual disability is considered undesirable. Contrary to the historical assumption that people with an intellectual disability are

better off with their own kind, one of the beliefs of social role valorisation is that association with others with an intellectual disability contributes to being perceived as devalued. Therefore, minimising the socialisation of people with intellectual disabilities with each other reduces their visibility as a deviant group and maximises their exposure to normality (Briton, 1979).

Szivos and Travers (1988) acknowledge that self-concept is at least partially dependent on the valuation attached to the various social groups to which an individual belongs. However, an alternative to dissociation from others with intellectual disabilities is to improve their social status through the acquisition of the values and attributes of advantaged groups or developing value systems of their own and eschewing certain main stream values.

In addition, sharing the experience of having a disability in an accepting forum can enable an individual to learn that disability can be spoken about and accepted. This can help to promote acceptance of self and better enable individuals to feel less fearful of rejection and enter into fulfilling interpersonal relationships.

CONTRASTING NIRJE AND WOLFENSBERGER'S CONCEPTS

Both Nirje and Wolfensberger's models of normalisation are consistent with a developmental model of disability which indicates that all individuals have the capacity for developing progressively higher levels of skill given that appropriate training and educational services are provided (Neisworth & Smith, 1978). The developmental model contrasts with a deficit model which portrays people with an intellectual disability as sick, subhuman, a menace, as subjects of pity, or a burden of charity.

To translate normalisation into action one needs to consider the individual, the social system, and society at large (Foster, 1983). Individual approaches include presenting, managing, addressing, labelling and interpreting the individual in such a way as to emphasise similarities not differences. Social systems need to enable the person to be seen as culturally normal as possible. Societal values and attitudes also need to be shaped to ensure maximum acceptance of difference.

It is balance between these strategies which distinguishes Nirje's normalisation from Wolfensberger's social role valorisation (Wilson, 1993). Self determination is so central to Nirje's principle of normalisation that it includes the right to make mistakes in life (Nirje, 1972). This enables people to learn from their mistakes. Wolfensberger's social role valorisation takes a different view. His principle is less a statement of individual rights but a psychological theory based on how people are ostracised by society, which also tries to redress this mechanism by changing the perceived image of these people. The single most important goal of social role valorisation is to create or support socially valued roles.

Although Wolfensberger's focus on people conforming to society's norms is simply a form of socialisation, his conservatism corollary perhaps goes too far in that it can lead to over-control of the resident and less expectation of change on the part of society. However, the freedom associated with Nirje's normalisation may result in continued rejection by the community and contribute to a sense of failure or helplessness. Alternatively, there needs to be responsibility for change on the part of both the resident and the community.

EGALITARIANISM

Novak and Heal suggested in 1980 that egalitarianism may be an alternative to normalisation. They felt that stressing the importance of associating people with disabilities with enhancing imagery may be a good idea in theory but is not necessarily successful in practice. Their major concern was why the disinherited should emulate the disinheritor, as appears to be suggested by the Wolfensberger's 'conservative corollary'. They felt it would be more appropriate for the quality of "human-ness" to supersede all other qualities as the basis for human evaluation. Novak and Heal indicate that the assumption underlying normalisation is that people with a disability are good and valuable but weak and thus require compensatory services. Egalitarianism however, asserts that people with disabilities are simply manifesting individual differences within the normal range of the human condition. Any assistance is thus provided as part of a continuum of generic services that can be utilised by anyone.

DEINSTITUTIONALISATION

According to the principles of normalisation it is the right of the person with an intellectual disability to be treated as any other adult and live in as normal an environment as possible. Normalisation thus fosters deinstitutionalisation and the development of community based living arrangements and the least restrictive environments that facilitate involvement in mainstream society. Although deinstitutionalisation and normalisation are both predicated on the goal of improving the quality of life of those with intellectual disabilities, they are not the same thing. Normalisation does not specify treatment but simply intends to afford to devalued people the full dignity to which they are entitled.

Deinstitutionalisation means more that just the physical removal of people with an intellectual disability from institutions. It also involves reducing admissions to those institutions through the development of community alternatives, returning appropriately prepared individuals to the community, and reforming institutions so that they are consistent with human rights and promote the development of skills required for a return to community living (Novak & Heal, 1980). Checklists such as Gunzburg's 39 steps (Gunzburg, 1973) have been developed as a basis for discussion in order to determine what needs to be changed in a residential setting to achieve greater normalisation. The questionnaire covers areas such as rigidity of routine, 'block treatment', depersonalisation and social distance, as well as physical characteristics of the environment.

SUMMARY

The current emphasis on human rights and choice is closely tied to the ideals of normalisation. Normalisation has been conceptualised by Nirje and Wolfensberger in quite different ways. Nirje's concept of normalisation focuses on providing a normal environment, while Wolfensberger's social role valorisation emphasises eliciting normal behaviour in the person with the intellectual disability.

Nirje's approach focuses primarily on normalising the environment and fully encompasses increased choice. This approach may be valued for its own sake because it provides decent life-conditions; considers the

personal needs of residents; and provides opportunities for meaningful and enjoyable activities, and developing viable peer relationships. There is a strong connection between the normalisation principle and exercising choice (Goode & Gaddy, 1976), and decision-making (Jenkinson, 1993).

Wolfensberger's approach on the other hand emphasises the goal of reducing the perception of deviance in order to gain the expected rewards of a valued member of society. The consequence of this can be disregard of personal choice. One of the key differences is thus the importance of choice.

Chapter Three

DEINSTITUTIONALISATION

HISTORICALLY

People with an intellectual disability have traditionally been cared for within the nuclear or extended family. Although this has continued to be the case in the third world, institutional care became the norm in the Western World as social and economic conditions made care at home difficult. Furthermore, the presence of people with intellectual disabilities in the community came to be perceived as a threat to community welfare as many people inaccurately believed that individuals with intellectual disabilities are not, and cannot learn to be, responsible for their own behaviour (Tymchuk, 1985).

The principle of person-environment fit led to the construction of institutions designed to provide a simplified and supportive community in which the social consequences of intellectual disability appeared less obvious and less devastating. However, the creation of public institutions also came to be founded on: a belief in, and emphasis on, the necessity for physical care of people with an intellectual disability not on their developmental needs (Cocks, 1985); and the protection of the community, as much as the individual.

This resulted in the provision of predictable and regimented services by medical personnel. Despite good intentions, this often led to rigidity; lack of opportunities to develop daily-living and self-care skills; inadequate programmes for learning new skills; superficial relationships between the sexes; and limited functional knowledge about the community (Cummins & Dunt, 1990).

According to Rowitz (1987), beliefs have come full circle and the problem of caring for people with an intellectual disability is again seen as a community concern rather than an institutional one. Institutionalised management practices are now believed to diminish the importance of the

individual, reduce autonomy, and promote the development of behaviours that are adapted to the institution rather than community norms, further isolating individuals from the rest of society (Cummins, Polzin & Theobald, 1990). The result is that the abilities of people with an intellectual disability have frequently been grossly underestimated. When given appropriate training and opportunities many can function at levels never considered possible (Perrin, 1982). Furthermore Clarke and Clarke (1974) indicated that IQ ratings are not constant and can change as a result of education and changing circumstances.

As segregated or specialised environments are now considered detrimental to the individual's development (Landesman & Butterfield, 1987), many reports on services for people with intellectual disabilities have recommended relocation of residents from hospitals into community houses (Molony & Taplin, 1988). Some see all large institutions as inherently degrading and resist efforts for upgrading the quality of institutions. Others question the universal value of deinstitutionalisation for all individuals, and the quality of care provided in some community settings (Landesman & Butterfield, 1987).

Deinstitutionalisation is just one consequence of changed perceptions of the potential and capacity of people with intellectual disabilities (Rowitz, 1987). It is based on the belief that moving into the community leads to a more normalised lifestyle, and enables the development of normal adaptive behaviour such as the freedom to interact, the ability to take risks, and to face the challenges of the environment. This results in greater expressed satisfaction with life, and increased leisure, living, social and vocational skills. Other benefits include greater independence through more varied life routines, a more extensive range of social activities, and more opportunities for personal choice in all aspects of life (Cummins & Dunt, 1990).

Zigler, Hodapp and Edison (1990) emphasised that the focus should be on improving the quality of the lives of those with an intellectual disability rather than on where that life is lived. The difficulty is in determining the types of environments and conditions that will enhance quality of life and personal life satisfaction (Landesman & Butterfield,

1989). Shameful conditions have been identified in institutions but there have also been model programmes conducted within institutions, and horror stories of deinstitutionalised people who are isolated, neglected, or abused in the community.

Deinstitutionalisation began in the late 1960's and early 1970's in the United States of America and Britain, and somewhat later in Australia (Molony & Taplin, 1988). Initially the focus was on mental institutions, only later extending to institutions for people with an intellectual disability. In many cases the deinstitutionalisation of those with a mental illness happened rapidly, and without appropriate planning for community alternatives. The deinstitutionalisation of those with intellectual disabilities has been a more gradual process which has, at least in some cases, benefited from the lessons learned from the earlier mistakes.

OBJECTIONS TO DEINSTITUTIONALISATION

According to Parmenter (1991), the success or otherwise of community based services will be moderated, to a large extent, by the degree to which society accepts people in their midst who have in the past been perceived as requiring segregation. Some of the concerns of parents and the community include worries about the stability and permanency of the new system, the quality of services, decreased accountability, adequacy of supervision, and the risk of exploitation.

However, the right to choose for oneself is a fundamental value in our culture and should also be a central component of deinstitutionalisation. People with a disability have the right to live where they choose, and it must be acknowledged that some of the resistance to deinstitutionalisation comes from the people themselves. Although residents have the right to enjoy living conditions that are acceptable for members of the community without disabilities (Brown, 1987), services should also take into account personal choice and the quality of life of the individual through the provision of a variety of options. Foxx, Faw, Taylor, Davis and Fulia (1993) developed a program to teach people with an

intellectual disability how to evaluate and select potential community living options.

LEAST RESTRICTIVE ALTERNATIVE

The least restrictive alternative (LRA) approach favours individual choice (Foster, 1983). LRA can be used as a means for making sure that each individual has available choices which restrict freedom to the minimum extent possible. The focus is to create less restrictive alternatives rather than reducing unduly restrictive choices. However, if a decision carries with it unnecessary restriction which may not be fully appreciated by a person with an intellectual disability or their advocate and this is not in the best interest of the individual, LRA may be regarded as an appropriate means to protect the person even though it may limit choice. Furthermore, it can be difficult to choose between two alternatives one of which is restrictive but familiar, or one which is less restrictive but less familiar. This can be dealt with by accepting the decision, transferring the decision to an advocate, or providing counselling to the individual.

Some believe that the approach, also known as the least restrictive environment (LRE), sanctions infringements on basic human rights to freedom and community participation. Taylor (2001) suggests that the LRE continuum implies not whether the rights of people with developmental disability should be restricted but to what extent. This is not considered appropriate for those who have not committed a crime and should not have their rights restricted. People with an intellectual disabilities should therefore, be able to live, work, and go to school in the same settings as other people, without having to earn the right to move to a less restrictive alternative.

RESIDENTIAL ALTERNATIVES

A number of alternatives to institutional accommodation are available for adults with intellectual disabilities including group homes, placement with a family, an independent bedsit or flat, supported lodgings, staffed houses, or homes shared with other tenants without disabilities or

a live-in volunteer (Burchard, Hasazi, Gordon & Yoe, 1991). There is a huge variability not only between but also within residential alternatives. Each differs in terms of organisation, structure, function, care practices, and involvement in the community, and thus result in differing degrees of normalisation.

Size and Staffing

Increasing the size of the residence has both benefits and disadvantages. The larger the population size, the more opportunities for social interaction, but the greater the likelihood of depersonalising practices which limit freedom of choice. However, quality of life is not related to size per se (Landesman-Dwyer, 1981), but also the quality of the interactions with support workers and other residents. Small facilities can be institutional in both atmosphere and lack of interpersonal relationships when support workers perceive themselves as in charge, rather than in a more supportive role.

Lack of adequate staff-resident interaction is often attributed to insufficient staffing but this is not necessarily so, as support workers tend to interact with each other rather than with residents (Molony & Taplin, 1988) and do not necessarily increase individual attention or improve the quality of staff-resident interactions (Landesman-Dwyer, 1981).

Residential facilities are also plagued with high staff turn-over rates, low pay scales, resistance from local communities, and problems in inter-agency co-ordination, all of which impact on the morale of the direct-care staff (Landesman-Dwyer, 1981). Morale, in turn, influences the quality of the service that support workers provide. The proposed solutions include more funding, greater family and community involvement, more normalised learning opportunities, and increased training for support workers and residents.

The report of the Joint Commonwealth and State Review into the needs of people with an intellectual disability in Tasmania recommends that a course common to all direct service staff in the field of intellectual disability be established (Foster, 1983). This would serve a number of purposes including promoting the view of staff as skilled professionals and

improving understanding of normalising practices. Ultimately though, the attitudes and expectations of the support workers toward the people they work with constitute the key. When support workers see their role primarily as assisting residents to live their lives as independently as possible in the community, the resident is more likely to have greater opportunities for autonomy and responsibility (Shaddock, 1994). This leads to greater skill development, behaviour improvement, community integration, and a greater sense of independence.

Resident Care Practices

The differences between residential alternatives are not just a function of size or level of staffing (Howell & May, 1980). Orientation of the care practices also influences residential services for people with an intellectual disability. This has partially been attributed to the training of support staff. However, for staff to utilise more resident-oriented care practices community attitudes towards working with people with disabilities need to be changed, so that support workers see themselves as fulfilling a valued role. When supporting people with a disability is a more highly valued occupation, McCormick, Balla and Zigler (1975) indicated that pay rates and training expectations are higher, and the care is much more oriented towards the resident.

Howell and May (1980) found that orientation of care also appears to vary according to the level of disability of the residents, being more institution-oriented for those with severe and profound intellectual disabilities. Again, the differences were not attributable purely to the size of units or the level of staffing but were related to the difficultly in providing a normalised environment when the level of disability requires a large degree of physical care.

INDICATORS OF SUCCESS

It is extremely difficult to predict the success of community placements, and the best approach appears to be to have a continuum of residences to meet the varied needs of individuals (Menolascino & Eaton, 1980). Benefits tend to increase if the move is individualised and

voluntary or leads to markedly improved living conditions. To maximise success it is important to prepare the resident for the move and greater self-sufficiency, and make provisions to protect their human and civil rights.

Resident Characteristics

The characteristics of the resident associated with successful community placement are not clearly identified due to the multifaceted nature of the individuals as well as their environments and life histories. Landesman and Butterfield (1987) found that successful adaptation to a new environment cannot be predicted from age, sex, family involvement, length of prior institutionalisation, training prior to moving, formal intelligence tests, or adaptive behaviour assessments. Although IQ and level of functional ability tend to influence which people are placed in the community, the evidence for higher functioning residents being more successful in community placements is not absolute.

Environmental Characteristics

It is essential that people continue to have access to the services they need (Rowitz, 1987) so that old problems are not traded for new ones by forcing people to live in hostile communities where there are few support systems, and a lack of social networks (Rowitz & Stoneman, 1990). To avoid long-term problems developing, Brown (1987) believes that professionally supported programmes need to be developed so that the disasters and atrocities of the institutions of the past will not be replaced by devaluation, lack of financial support, and isolation in the community.

Support Worker Characteristics

Support worker attitudes and expectations towards the people they work with play a major role in determining the quality of any residential placement. Good community placements can deteriorate due to inadequate support worker commitment, style of administrative support, and limited day-to-day opportunities for control over the environment.

According to Landesman and Butterfield (1987) what matters most is the quality of the care, as significant variation can occur within and between different forms of residential settings.

OUTCOMES

More normalised living environments provide similar opportunities for personal development and fulfilment as are available to other members of the general community (Cummins, Polzin & Theobald, 1990). However, Burchard, Hasazi, Gordon and Yoe (1991) indicated that the opportunities, training, and support necessary for increasing and maintaining improved adaptive functioning, and consequently quality of life, are not necessarily a function of the type of setting.

Normalised Experiences

A normalised routine involves daily variation in daily rhythm, more variable weekend patterns, and greater flexibility (Cummins & Dunt, 1990). In a study by Jones (1986), it was found that adults in the community had daily routines similar to those without disabilities of a similar age who were living away from home, including differences between weekends and weekdays. Residents also participated in a range of leisure activities and performed a number of regular chores such as their own washing, ironing, and keeping their bedroom tidy, while cooking was done on a roughly rotating basis. Regular house meetings were held to rotate chores and determine the menu and shopping list.

Skill Development

One of the aims of deinstitutionalisation is to assist the individual to become as independent as possible through the development of skills. Some research has demonstrated the phenomenal progress of previously institutionalised individuals after moves into community homes (Landesman & Butterfield, 1987), while other studies have found no major behavioural changes following similar moves (Dunt & Cummins, 1990). However, independence is difficult to judge as residents have a tendency to overstate their competence (Jones, 1986), reporting that they need no

help from support workers and see themselves as competent and able to take responsibility for their own actions.

Increased skill development in self-care, social interaction, language, domestic activity, and responsibility, and decreased threatening, violent, and untrustworthy behaviour can follow deinstitutionalisation (Dunt & Cummins, 1990). However, Barlow and Kirby (1991), found that the only significant difference between young adults with intellectual disabilities who lived either in a residential institution or who had moved into independent community accommodation was in their reported residential satisfaction. Those in the institution were more satisfied with their social life, while those in the community were more satisfied with their autonomy.

In a study examining the closure of an institution in Queensland by Young, Ashman, Sigafoos and Grevell (2001), choice making and life circumstances were found to improve considerably following relocation to the community. More opportunities for choice-making are available and residents are living in a way that more closely approximates those without a disability. Gains may have been due to relocation and the changed lifestyle, but may also have been the result of the changed service delivery model which encouraged staff to facilitate communication and choice-making through the use of communication aids and allowing extra time for individuals to indicate their wants and needs.

Rock (1988) found that residents reported that the main advantage of living in the community was the feeling of being independent because independence meant control, choice and power over the management of their lives. However, in a longitudinal study by Birenbaum and Re (1979), residents were able to develop more personalised social relationships with their peers following deinstitutionalisation, but still remained dependent on support workers for many services they could probably learn to perform themselves. These researchers also reported that, after moving to the community, residents were making more choices about when to go to bed and get up, when to get haircuts and when to take showers, and there was a trend towards increased responsibility and self-reliance, although greater familiarity with the wider community did not occur. However, an initial

period of personal exploration and acquisition of new experiences gave way to a prosaic routine of sleep, work, and at-home recreation of a passive nature.

Stability of Change

Although life skills have been shown to improve after deinstitutionalisation it is unclear whether this is transitory due to the challenge and excitement of a new living environment and renewed support worker enthusiasm, or an ongoing benefit of the move (Cummins, Polzin & Theobald, 1990). However, in Cummins, Polzin and Theobald's 1990 follow up study of the deinstitutionalisation of St. Nicholas Hospital, there was evidence of continued life-skill acquisition four years after the move into the community.

Increased functioning and engagement in domestic activities following deinstitutionalisation may be due to substantially increased opportunities for expression (Felce, de Kock & Repp, 1986). However, skills improve over time at different rates for different people and may not only be a result of living in a less restrictive environment but also due to formal and informal programming to teach new skills and modify inappropriate behaviour as well as more autonomy, increased access to resources, and clear expectations by support workers of increased independence (Seltzer, 1981).

SUMMARY

Deinstitutionalisation and community integration is an attempt to provide residents with a more normalised lifestyle and improved living conditions, as well as opportunities to increase skills and adaptive behaviour, in order to facilitate greater choice and control. However, deinstitutionalisation is not a guarantee of positive change, and many factors are involved in the fit between resident and residence including individual, environmental, and support worker characteristics.

It is also essential that appropriate supports continue to be provided in order to maintain the resident in the community and care needs to be exercised to maintain the standards of any residence as, over

time, adverse changes in support worker commitment, administration, or resources can occur in community placements just as they have done in institutions (Cummins, Polzin & Theobald, 1990).

Community involvement, and support workers expecting and encouraging skill development through the provision of opportunities and training programmes are among the strongest predictors of the success of a residential placement regardless of size or location.

Chapter Four

EXPERIENCES OF CHOICE-MAKING

INDEPENDENCE

The principles of normalisation, and recognition of the right to autonomy, have led to, and been founded on, an emphasis on independence. Independence is an infinitely variable self-concept, unique to the individual, which concerns control and choice rather than any absolute measure of competence (Rock, 1988). Independence involves choice, control, and power in, and over, the management of our lives and the environment in which we live. Definitions of independence cover five main areas: risk-taking, privacy, decision-making, organisation and control, and encouragement. The five areas all involve an element of choice and independence is meaningless without some level of choice being exercised (Rock, 1988).

The concept of normalisation is associated with a shift from the notion of the *'professional knows best'* to independent or shared decision-making. Menolascino and Eaton (1980) predict that in the future people with an intellectual disability will be allowed to decide issues far more independently than they have in the past. As people with an intellectual disability model their behaviour on the people they meet, those who work with people who have an intellectual disability need to model effective decision-making in situ whenever the opportunity or necessity arises (Brown, Bayer & Brown, 1988).

Right to Autonomy

It is widely acknowledged that choice-making is a valued and intricate part of life and that the ability to exercise choice increases personal autonomy and enhances perceived independence, dignity and self worth (Houghton, Bronicki & Guess, 1987). The choices and preferences we express, and the decisions we make, define ourselves

because they reveal our values, priorities, goals and needs, as well as our feelings about the present and our hopes for the future. Freedom of choice is a way of asserting one's identity and most individuals treasure, and fight to retain this freedom (West & Parent, 1992).

Historically, this freedom has often been infringed upon in the name of the resident's best interests, resulting in life experiences and opportunities for independence being seriously curtailed (Shaddock, Zilber, Guggenheimer, Dowse, Bennett & Browne, 1993). Recent changes in societal values and public policy have resulted in increased recognition of the rights of people with intellectual disabilities to autonomy, similar to other citizens of similar age in the same country.

Every person, regardless of disability, has the right to communicate with others, to express everyday preferences, and to exercise at least some control over their daily life. However, it is not enough simply to offer alternatives (Cullen, 1999). Each person should be given the choice, training, technology, respect, and encouragement to do so. Learning to make good choices requires experience with the process of decision-making, with viable alternatives, and with the consequences of decisions. If independent choice is not feasible or safe, the choice can often be adapted or supported so the individual may at least partially participate (West & Parent, 1992). People should be allowed to exercise as much choice as their abilities allow, even if this involves simply expressing a preference.

Daily Choices

The right to autonomy is a fundamental right even with regard to apparently trivial matters (Jenkinson, 1993). Historically, people with an intellectual disability have had significantly less choice than the general community even about aspects of their daily lives such as what to wear and what to eat. Maximum independence and autonomy implies that residents should make their own decisions, as far as possible, whether these are major decisions, or trivial ones with only transitory consequences (Jenkinson, Copeland, Drivas, Scoon & Yap, 1992). In their review of studies of deinstitutionalisation in the UK and Ireland,

Emerson and Hatton (1996) found that residents have more choice over routine daily activities in less institutionalised settings, but that residents had little choice over important life decisions in any residential setting.

However, choices are sometimes limited only to expressions of preference in relation to basic daily human functions like eating, drinking and going to the toilet, as there is an expectation that people with severe intellectual disability cannot make anything other than here and now choices (Shaddock, Zilber, Guggenheimer, Dowse, Bennett & Browne, 1993) . Although this may be an unnecessary restriction, basic daily living choices are an important place to begin making choices. These choices may not appear significant, but for those who rely on others for personal care and assistance, they are of prime importance for feeling a sense of control over their lives.

People with an intellectual disability often lack choice-making skills, experience, and opportunities to choose even in these basic areas (Parsons & Reid, 1990). They may require extensive assistance to develop the skills necessary for exercising choice not only in the major life decisions but also in the minor, day-to-day decisions (Shevin & Klein, 1984). March (1992) believes that the philosophy of normalisation will have only succeeded when the number of choices available to a person with an intellectual disability approaches that of the general community.

Defining Choice

Choice has been defined in different ways by different researchers. Definitions generally have at least some of the following components: that there are at least two alternatives, that selection is free and uncoerced, and that the options are preferred and familiar. The definition which will be favoured in this thesis is that choice is: *making an unforced selection of a preferred alternative from two or more options* (Stancliffe, 2001). This definition enables an emphasis on actively making a selection rather than passively complying with that put forward by another.

Competence

For most people, control over their lives through independent decision-making, is developed in adolescence. However, intellectual disability, by definition, includes significant impairments in qualities that are important in decision-making such as discretion, social competence, and understanding of one's own self-interest, as well as more general cognitive impairments (Jenkinson, 1993). Consequently, the assumption is often made that people with intellectual disabilities are not capable of making choices or decisions. This denies them the respect given to most people in the community (Wehmeyer, 1992). Intellectual disability should not be the sole criterion for determining competence in decision-making, as the presence of an intellectual disability is not synonymous with incompetence in all areas (Jenkinson, 1993).

For people with an intellectual disability to be given the chance to make decisions, support workers and society generally need to take into consideration the cognitive limitations and reduced experience of the individual, while at the same time enabling maximum control over options, through clear presentation of alternatives, and assisting with decision-making without pressure or influence (Jenkinson, 1993).

Learned Helplessness

A history of lack of consultation about decisions may result in subsequent reluctance to participate due to a sense of inadequacy, and uncertainty about making choices now (Shaddock, Guggenheimer, Rawlings & Bugel, 1993). Learned helplessness can result, and lead to greater passivity, negative expectations, withdrawal, and the tendency toward self-depreciation, as well as loss of self esteem, decreased ambition, emotional disturbances, and chronic reactive depression (Guess, Benson & Siegel-Causey, 1985). Many experience ambivalence with regard to being more directly involved in decision-making processes and claim they are happy with the decisions made for them as they believe their support workers 'know best' (Brown & Ringma, 1989). Thus the consequences of learned helplessness can compound an individual's existing disability, leading to the appearance of even greater deficits.

Those who score low on learned helplessness have also been found to make more competent and appropriate decisions than those that score high (Jenkinson, 1999).

This may explain the findings of a study by Neumayer and Bleasdale (1996) into the personal lifestyle preferences of people with an intellectual disability. Although 90% of residents in this study reported that it was important to be independent, 43% responded that it was not important to have plenty of choices or they preferred few choices. The reasons given were that it gets too confusing, becomes overwhelming, or fewer choices are easier. It is important that resident reactions of this type be considered when choice is introduced so that it does not become a negative experience.

Although deinstitutionalisation is intended to result in more quality services, it is not the structure of the residence which determines quality. For people with limited independence normal opportunities are not sufficient as independence requires opportunity, personal support, and effective assistance. Ideally, individuals should experience control over situations beginning early in life (Wehmeyer, 1992) as people suffering from learned helplessness can be highly vulnerable to the influence of others (Jenkinson, 1993). If people feel that no matter what they do, that someone or something other than themselves controls them, they may go through life doing what other people tell them to do (Tymchuk, 1985).

Dattilo and Rusch (1985) believe that the introduction of choice may be critical in the prevention and amelioration of learned helplessness. The opportunity to learn to perform a task independently or semi-independently, to experience a sense of accomplishment, to feel in control of a situation, to try despite the risk of failure, and also to fail, are important needs which can result in longer life spans and greater happiness (Guess, Benson & Siegel-Causey, 1985).

Cycle of Incompetence

Unfortunately, many people with an intellectual disability are trapped in the cycle of incompetence. This cycle begins with the perception that those who lack choice are incompetent. When people

believe that individuals with intellectual disabilities are not capable of making choices or decisions, or at least not the kinds of choices that their support workers perceive to be in the best interests of that person (Guess, Benson & Siegel-Causey, 1985), opportunities may be further limited. Lack of access to choice opportunities may then result in the people perceiving themselves as incompetent, and thus making fewer choices even when the opportunities arise. The individual is then perceived to be even more incompetent and fewer opportunities are made available and the cycle of incompetence is perpetuated.

It is therefore important to work both on the community's perceptions of people with intellectual disabilities as individuals capable of making appropriate choices, and also on the individual's own perceptions of themselves as competent. Both of these goals can be achieved by increasing opportunities for, and participation in, choices regarding all aspects of the person's life (Guess, Benson & Siegel-Causey, 1985).

Supporting Choice

Interdependence

Traditionally, people with severe intellectual disabilities have been taught compliance, and the current emphasis on independence and self-reliance (Shevin & Klein, 1984), can lead to the individual feeling isolated and confused if appropriate supports are not available. It is particularly difficult for people with high support needs to become more autonomous without considerable support (Shaddock, Guggenheimer, Rawlings & Bugel, 1993). However, if the aim becomes interdependence then the individual may end up being considered an equal member in a team, where others' opinions are given as much weight as their own. Ideally, interdependence should simply enable people with an intellectual disability to access the supports required but ultimately be free to make their own choices as independently as possible (Jenkinson, 1993).

Skill Development

Although people with intellectual disabilities tend to be more like other people than they are different, they are not the same and without

additional, individual supports, they are unlikely to develop the skills required to increase their independence. Independent functioning requires access to opportunities as well as the capacity to participate in those opportunities (Guess, Benson & Siegel-Causey, 1985). Existing skill development is individual, as is the ability, and time required, to develop new skills (Brown, 1988), but many skills are most effectively learnt in normal everyday settings. Furthermore, the earlier choice skills are developed, the easier it becomes to make choices in the future (Ficker-Terrill & Rowitz, 1991).

The focus of services needs to be on recognition of the ability of people with a developmental disability to control their own environment through the acknowledgment of capabilities, and a focus on a cycle of competence. According to Brown, Bayer and MacFarlane (1989), many of those with a developmental disability have a clear knowledge of their needs and requirements but lack of consultation has reduced their confidence, motivation and assertiveness. When residents are given the opportunity to make choices, they are perceived as capable of making choices, and are consulted about other decisions that concern them (Parmenter, Briggs & Sullivan, 1991).

Real Choices

The right to choice should perhaps be elaborated further and become the right to make uncoerced choices. Habilitation, the teaching of skills needed to live as independently as possible, often results in services exercising a great deal of control over the lives of residents with developmental disabilities (Bannerman, Sheldon, Sherman & Harchik, 1990). Personal liberties such as freedom from undue restraint, freedom of speech, freedom of religion and the right to control our own lives free from coercion and compulsion are often compromised in what is perceived as the resident's "best interest". Their "best interest" is often defined as what leads to an independent, "normal" lifestyle (Jenkinson, 1993). However, the absence of both everyday choices and major decisions can be detrimental to quality of life, and does not equate with normality.

People with an intellectual disability often have only the choices that their support workers or families allow them to have, or even none at all (Stancliffe, 1991). This is because support workers tend to determine the range of alternatives, and may interpret lack of preference, inability to suggest an alternative, or compliance as active choice (Kishi, Teelucksingh, Zollers, Park-Lee & Meyer, 1988).

Choice is only meaningful if there is more than one available option and when a response will change the outcome. Even when the preferences and interests of the resident are considered and accurately identified, it is not a real choice if they are simply asked to consent to another's decision (Jenkinson, 1993). Furthermore, support workers' opinions of preferences do not coincide highly with systematic assessments of resident preference, and thus should not be relied upon (Green, Reid, Canipe & Gardner, 1991). Pseudo choices are when a choice is offered but the response is anticipated and acted upon before the resident has a chance to respond (Shaddock, Zilber, Guggenheimer, Dowse, Bennett & Browne, 1993).

Choices should also include the possibility of selecting none of the options offered, or choosing when to stop an activity. However, if a negative response is considered unacceptable due to duty of care or other reasons, then the appearance of choice should be avoided in order to avoid confusion. It is preferable to offer alternative means of accomplishing the desired objective, offering a choice of partners or assistants with the activity, or a choice of times for completing the task.

OUTCOMES OF INCREASED CHOICE

As well as increased quality of life (Shaddock, Zilber, Guggenheimer, Dowse, Bennett & Browne, 1993) choice is involved in many higher-level personal skills such as assertiveness, problem-solving, handling feelings, sexuality and long-term planning (Kishi, Teelucksingh, Zollers, Park-Lee & Meyer, 1988). Increasing opportunities for choice has been related to a number of positive educational outcomes (Kennedy & Haring, 1993). One of the key findings is that self-management and

choice can be an effective tool for increasing adaptive, and decreasing maladaptive behaviour (Wehmeyer, 1992). In particular, choice has resulted in enhanced performance, increased participation and satisfaction, and a decrease in problem behaviours.

Enhanced Performance

In an investigation of the impact of choosing the response words to be learned in a paired-associate learning task, Monty, Geller, Savage and Perlmutter (1979) found that choice enhanced performance and believe that it was perceived control that resulted in increased motivation not the choice of words per se. Choice-making has also been found to have positive effects on learning rate (Shevin & Klein, 1984). The positive effect of choice is believed to only be present when the choice is meaningful, an unattractive choice is perceived to be equivalent to no choice at all.

Increased Satisfaction and Participation

Individuals appear to prefer situations in which they have choice. People with intellectual disabilities also select, and appear to participate more, in activities which involve choice (Bannerman, Sheldon, Sherman & Harchik, 1990). Helping residents to make choices can increase resident satisfaction and result in their willingness to participate and succeed in the activities they have chosen. However, forced choice can inhibit interaction because the person presenting the choice retains all the control.

Dattilo and Rusch (1985) found that people with severe disabilities participated more in activities when they were able to regulate their involvement themselves, and Kennedy and Haring (1993) found that activity increased when residents were engaged with preferred stimuli. Behaviour management procedures that incorporate choice have also been found to reduce social avoidance behaviour, increase spontaneous communication, and improve task performance (Dyer, Dunlap & Winterling, 1990), as well as leading to greater spontaneous and prompted interactions with others (Houghton, Bronicki & Guess, 1987).

Parsons, Reid, Reynolds and Bumgarner (1990) found that the opportunity to choose a work task resulted in increased attendance to the task, but assigning the resident to a preferred task was as effective as giving the resident the opportunity to choose. The explanation for this was not clear and they felt that further work was needed in order to identify the conditions in which choice-making beneficially affects the activities of people with severe disabilities. However, Dunlap, dePerzel, Clarke, Wilson, Wright, White and Gomez (1994) found that choice was superior to no choice even when the option had previously been identified as preferred.

Quality of life can thus be improved by taking into account the likes and dislikes of individuals with an intellectual disability and by encouraging them to make choices regarding the programmes they are involved in. However, it must be recognised that preference hierarchies are idiosyncratic for each individual. They are not fixed over time so the individual's choice, rather than knowledge of preference hierarchies, should be the focus. The best solution may be to offer choice from a menu of preferred options (Newton, Ard & Horner, 1993).

Decreased Problem Behaviours

The selection of rewards as well as tasks and materials can also demonstrably reduce problem behaviours (Dyer, Dunlap & Winterling, 1990). Problem behaviours appear to be exhibited less frequently when an individual has opportunities for choice. The reduction in aberrant behaviour and greater compliance in activities involving choice may be the result of receiving a preferred outcome (Bannerman, Sheldon, Sherman & Harchik, 1990).

A preferred activity is one selected in the past from among several options, while a choice is that selected at a particular moment in time. Studies examining the differential effects of preference versus choice have produced mixed results, some show that choice leads to increased improvements in behaviour over assigning preferred alternatives, in others choice and preference have been equally effective in producing behaviour change (Romaniuk & Miltenberger, 2001). As assigning preferred tasks

has never been shown to produce increased improvements over provision of choice opportunities, choice may produce additional advantages in reducing disruptive behaviour.

A possible explanation for this finding is that problem behaviours are attempts to escape non-preferred events or the directions of others (Bambara, Koger, Katzer & Davenport, 1995). The reinforcement of engaging in a preferred task, that is either provided or chosen, thus outweighs the reinforcement gained by engaging in the problem behaviour. The additional benefit of choice may be due to the act of choosing and a perceived increase in control (Romaniuk & Miltenberger, 2001). This explanation suggests the potential for deleterious effects when opportunities for control are withheld after a period of choice, and the importance of not equating choice and preference.

LIMITATIONS ON CHOICE

There are a number of limitations on the choice-making of any individual whether they have an intellectual disability or not. Limitations can include personal, environmental, or interpersonal factors, and these will be related to people with an intellectual disability in terms of resident, environmental and support worker factors (Stancliffe, 1991). Environmental factors contribute to the availability of opportunities for choice. Support worker factors are due to the need to communicate preferences to others, and for these expressions be encouraged, recognised and responded to by others (Shaddock, 1993). Resident factors, both real and perceived, influence whether opportunities for choice are taken advantage of or not.

Resident Limitations

Resident Experience

People with intellectual disabilities often lack the experiences required both to develop preferences, and to understand the processes involved in choice-making (Kishi, Teelucksingh, Zollers, Park-Lee & Meyer, 1988). The provision of opportunities to express preferences and

make choices does not mean that residents recognise, or know how to respond, to those opportunities (Stancliffe, 1991). It is also difficult to have preferences when the alternatives have never been sampled, and residents may even lack understanding of what it means to have a preference. Even when the options are familiar, an unfamiliar setting can result in a lack of response due to insufficient experience to enable the generalisation of choice-making skills.

Resident Expectations

Negative expectations about a resident's ability to respond to choice opportunities, whether those expectations belong to the support worker or the resident, can impact adversely on opportunities due to the cycle of incompetence (Jenkinson, Copeland, Drivas, Scoon & Yap, 1992).

Kennedy and Haring (1993) felt that choice may not always be a preferred or positively reinforcing outcome for some people, particularly if the resident feels judged or criticised when they attempt to make choices. The emotional consequences of choice-making and the potential motivational implications will therefore need to be addressed.

If attempts to make choices in the past have not been recognised or honoured, an individual may not believe they have, or are capable of exerting, any control and thus will not take attempt to take an active part in their own life. An emphasis on competencies rather than limitations, continually identifying opportunities, and providing appropriate supports for the person to express their wishes may promote daily choice-making and improve self-confidence (Siegel & Kantor, 1982).

Skills

Lack of skills is one of the major restrictions on the choices available to people with an intellectual disability (Shaddock, Zilber, Guggenheimer, Dowse, Bennett & Browne, 1993). Cognitive deficits tend to restrict the individual's ability to integrate new information and evaluate risks and benefits. This means that residents are less likely to follow an optimal decision-making process (Jenkinson, 1993), and may rely on habit or be susceptible to influence or bias. As a result choices may be limited to those that are concrete or involve an immediate action, involve only two

options or require a yes/no response, and involve only minor life-style change. However, choices need not be so limited that options are artificially preselected and restricted, leaving just the avoidance of undesirable alternatives or threats, and not real choice (West & Parent, 1992).

Other skill deficits that may interfere with the decision-making process include: limited attention spans, shifting values, and emotional reactions resulting in biases. Emotional reactions can occur when there are a large number of options or conflicting values and preferences, and the outcome becomes uncertain or risky. One of the biases that may result is to select an alternative, if it meets an important goal, without further consideration of other options (Jenkinson, 1993).

Increased support may be required to help compensate for any deficits (Stancliffe, 1991) , as lack of information can exaggerate deficits in choice-making skills. Shaddock, Rawlings and Guggenheimer (1993) indicated that there appeared to be a marked lack of information given to residents about many situations in which a choice could be available. This can only be overcome by support workers making the identification and support of choice opportunities a priority, although this can be difficult to achieve given their already heavy workload.

Communication

Communication problems can limit choices either through the resident not understanding the choice opportunity, or others not understanding the resident's attempt to convey their selection. This is due to cognitive, physical, communicative, or sensory impairments impeding expression and understanding (West & Parent, 1992). Communication can be aided by offering choices using the actual options or familiar symbols, however choice remains limited when the resident lacks the means to identify, suggest, or express an alternative to the options offered.

Furthermore, the voice of people with an intellectual disability is frequently lost through the reinterpretation of their perspectives by professionals (Brown & Ringma, 1989). Support workers may assume

that lack of protest is equivalent to consent, that habitual behaviour is the same as active choice and resignation is actually contentment (Shevin & Klein, 1984). Residents may communicate through idiosyncratic and non-conventional means in addition to words or gestures, resulting in greater likelihood of misinterpretation.

Environmental Limitations

Society

Although, freedom of choice is a highly valued right in our society, no individual is completely autonomous or self-determining. Choices must be made within cultural and family contexts, and can also be influenced by education and lifestyle. All people operate within certain constraints but we are free from constraints to the extent that we recognise the point where our freedom to operate ends and society's exercise of control begins.

In order for choice to be meaningful the options given must be within the parameters of acceptable behaviour (Shevin & Klein, 1984). Limits should be real and equivalent for all members of society, not arbitrarily narrow due to identification with a devalued group or determined by the biased expectations of others.

Resources

Another of the major constraints on the availability of choice is lack of resources. Money and the lack of it often limit the possibilities available. A related problem is the availability of transportation, which further limits access to options and reduces independence. Although these limitations are true for all members of the community, people with an intellectual disability are more likely to be in the lowest socio-economic groups due to limited earning capacity.

Group Living

Another of the major influences on the number and type of daily choices available is the number of people living in a household. This is due to the necessity for joint decisions and sharing responsibility for household tasks. Rosters, turn taking, and fair allocation of chores can

accommodate individual preferences, however the success of these arrangements depends on individual skills in arranging and carrying through independent activities, how well housemates get along with each other, and how skilled they are at resolving problems (Kishi, Teelucksingh, Zollers, Park-Lee & Meyer, 1988).

In a group home context Shaddock, Rawlings and Guggenheimer (1993) indicated that when one resident is more vocal, support workers can either accept the status quo, encourage the others to initiate more, or attempt to arrive at a group consensus. Whichever the option selected, the choices of some are likely to be limited due to the dynamics of group living. These researchers also observed that another consideration resulting from group living is that choices are not always consequence-neutral for others and this can impact on the type and extent of choice-making which is considered permissible.

Support Worker Limitations

Duty of Care

One of the primary reasons that support workers give for restricting opportunities for choice-making is "duty of care" (Jenkinson & Nelms, 1994). This is based on the legal requirement that support workers, in a position of responsibility for people who are considered less than competent, must not allow those people to come to harm. Some of the areas identified by support workers as requiring the most assistance or intervention include: budgeting and management of money, health, hygiene, medical care, human relations and social encounters, living situation, and "inappropriate activities" (Jenkinson, Copeland, Drivas, Scoon & Yap, 1992).

Unfortunately, this can lead to over-cautiousness and the perception of people with intellectual disabilities as incompetent to make any decisions. Although most agree that personal preferences should not take priority over the potential for life threatening outcomes, there is considerable scope for increasing self-determination through enhancing choice in areas which do not involve health or safety issues (Wehmeyer, 1992). This can only be achieved if support workers are given explicit

guidance on how to balance choice-making for residents with their responsibilities and the legal implications of those responsibilities (Shaddock, Rawlings & Guggenheimer, 1993). Even within the riskier areas, when some choices are clearly inappropriate, it is not necessary to exclude choice all together as choices such as when, how, and who to assist may still be possible.

Support Worker Expectations

The very nature of limited intellect seems to preclude people with an intellectual disability from being their own advocates because they are thought to be lacking in basic competence (Siegel & Kantor, 1982). People with an intellectual disability tend to learn more slowly, learn less, and forget more easily than most others. As a result, many people believe that an individual with an intellectual disability is not, and cannot learn to be, responsible for their own behaviour (Tymchuk, 1985). However, a major reason that individuals with an intellectual disability experience powerlessness, has less to do with their limitations and impairments, and more to do with the attitudes and practices of caregivers. Consequently, the ability of people with intellectual disabilities to be independent has been seriously underestimated and their potential is often largely untapped. (Shaddock, Guggenheimer, Rawlings & Bugel, 1993).

Support workers often claim that they recognise capabilities and consult residents about decisions as well as provide both opportunities and time to make choices, but the development of residents' choice-making skills is frequently lacking (Jenkinson, 1993). Support workers may not be competent to judge the resident's capacity for making decisions, but their judgement still affects the extent to which residents have opportunities and are encouraged to participate (Jenkinson, Copeland, Drivas, Scoon & Yap, 1992).

Kishi, Teelucksingh, Zollers, Park-Lee and Meyer (1988) found that the choices available to people with intellectual disabilities tend to be more limited the lower-functioning a person is considered to be. However, the perceptions of others regarding disability level are not necessarily equivalent to more objective measures of functioning. Although support

workers believe that residents should be encouraged to participate in decision-making, they felt constrained by lack of resources or options, and a lack of decision-making skills on the part of the resident (Jenkinson, Copeland, Drivas, Scoon & Yap, 1992). Support workers' expectations of residents' inability to participate may even inhibit them from offering a choice at all. Options can also be limited to suit the lowest common denominator when people with intellectual disabilities are presumed to have a homogeneous set of needs, abilities, desires, and limitations. (West & Parent, 1992).

There is also some ambiguity in support worker perceptions regarding what constitutes a choice. When support workers assume they are familiar with resident preferences they may interfere with choice through limiting options, or questioning responses they believe the resident will be unhappy with (Shaddock, Rawlings & Guggenheimer, 1993). Even when assumptions regarding preferences are correct, questioning a choice is generally not conducive to the effective development of independent skills. Furthermore, it has been found that support workers do not necessarily know the exact hierarchy of preferences and thus their assumptions may well be mistaken (Parsons & Reid, 1990).

Expediency

The choices of adults with intellectual disabilities can be limited as a result of expediency. Support workers may find it easier to make decisions on behalf of the residents, or at least strongly influencing decisions by emphasising particular options or failing to provide sufficient information about alternatives.

Shaddock, Rawlings and Guggenheimer (1993) found that legitimate choices can be at risk of not being honoured due to inconvenience to support workers. Staff working in group home settings have a great deal of responsibility, and when those they work with have limited experience in making choices, a considerable amount of effort may be required to present choices in an appropriate way. Often it is easier to make decisions according to the support worker's own interests or

preferences, or place greater importance on the maintenance of routines and scheduling of activities than on individual preference (Bannerman, Sheldon, Sherman & Harchik, 1990).

Knowledge

As can be seen from many of the areas above, it is frequently the lack of support worker knowledge regarding the best ways to offer opportunities, and to support and encourage resident skill development and empowerment, which interferes with the development of choice-making skills.

In Parmenter, Briggs and Sullivan's 1991 study, the majority of support workers indicated that they were involved in training decision-making. Despite this, residents reported that they had little or no say in day-to-day activities, and individual programme plans suggested that the development of residents' choice-making skills was not actively pursued. Although support workers may be aware of the importance of choice-making for quality of life, many appear to lack instruction, and perhaps sufficient motivation, to achieve this. The abilities of support workers to recognise the potential for residents to express preferences and make choices given adequate support, training and experience, may need to be addressed through training.

The way in which support workers tell or suggest to residents what to do can affect not only the choices made but also the opportunities for learning about how to make choices. Other support worker behaviours that can act as a deterrent to decision-making include: disregard of resident anxiety; infrequent opportunities; ambiguity of options; inconsistent recognition and acknowledgement of residents' responses; and the presentation of instructions as choice. Training can help to overcome these problems by teaching support workers how to replace suggestions, reminders or instructions representing no real choice, with opportunities to develop choice-making skills. They can clarify options, model the consideration of consequences, acknowledge and encourage responses, and assist residents to follow-through with their choices as independently as possible.

SUMMARY

The provision of normal opportunities for choice can reflect favourably on related skills, perceived independence, dignity and self worth. Dyer, Dunlap and Winterling (1990), found that choice-making opportunities have other potential benefits such as reducing social avoidance behaviour, increasing spontaneous communication and improving task performance.

Empowerment is the transfer of control over the values, decisions, choices and directions of human services from external entities to the individual. It is found to result in increased motivation to participate and succeed and a greater sense of dignity (West & Parent, 1992). However, people with severe disabilities have not typically been provided with many choice-making opportunities, and research is needed to determine how more opportunities to make choices can be made available.

Although the choices of all people are constrained in various ways, the limitations on people with intellectual disabilities appear to be more extreme. Thus, one of the possible roles of training is to help support workers to reduce the impact of those limitations in order to promote freedom of choice and maximise quality of life. Both the resident and the support worker need to gain a clearer understanding of what choice is and work on developing the skills required.

Chapter Five

CHOICE MODELS

DEVELOPMENT

Learning to make decisions is part of the normal developmental process but Shevin and Klein (1984) suggested that people with a severe intellectual disability do not receive the same opportunities to learn the skills involved in choice-making, or to practise making choices (West & Parent, 1992), as those without disabilities.

Development of choice-making skills usually begins when the accidental movement patterns of infants are interpreted with significance by the caregiver (Guess, Benson & Siegel-Causey, 1985). The infant gradually recognises this and responds by intentionally repeating the behaviour. Consistent response to these behaviours encourages the development of a systematic mode for communication as the infant learns to initiate and terminate interactions through eye contact, body movement, facial expression and vocalisation.

These behaviours come to be used to express the preferences of the child, and the responsiveness of caregivers is critical in the early development of communication skills and as an avenue for the exchange of information (Houghton, Bronicki & Guess, 1987). However, for children with an intellectual disability, knowledge of the disability may inhibit the caregiver from interpreting the behaviour as significant, thus depriving the child of an important early means of expressing preferences.

The most appropriate place to learn and develop many skills is in the real world, often by simple exposure and modelling, but the parents of many children with disabilities do not teach even the most basic of these skills despite the capability to learn (Brown, 1988). This is often the consequence of an emphasis by parents on their supportive and protective role, and the problem that assertive behaviour can be disruptive, idiosyncratic and time-consuming. Although assertiveness may initially

appear negative, in the long term these skills enable the individual to express choice, become more independent, and thus enhance their quality of life.

Many parents of children with intellectual disabilities want the same opportunities for their children as for those without disabilities, and they make the assumption that the educational environments suitable for normal children are therefore suitable for children with disabilities. However, children with intellectual disabilities frequently require additional supports to take advantage of opportunities (Brown, 1988).

Greater opportunities for normal interaction and the right to take risks helps promote the acquisition of many basic skills (Brown, 1988). Most of us are expected to take more responsibility for making important life decisions as we grow older Freedom of choice is a way of asserting one's identity and thus is a major task of adolescence (Jenkinson, 1993) but people with intellectual disabilities are often denied this opportunity. There is often a presumption of total incompetence because there are significant impairments in areas such as adaptive behaviour, discretion, social competence and comprehension of own self-interest (Jenkinson & Nelms, 1994). As a result, decisions are often made in the person's perceived best interests rather than choice being made by the individual, or at least according to the person's expressed preferences. This may result not only in the person with an intellectual disability being denied the opportunity to make major life decisions but often they are prevented from making even minor daily choices as well.

NEED FOR TRAINING

For children without disabilities little or no formal attention is paid by parents or in school to the establishment of skills related to autonomy and to choice-making, but children generally acquire such skills regardless (Shevin & Klein, 1984). However, due to the supportive and protective approach taken toward many children with intellectual disabilities, the chances for normal interaction and risk-taking, which can promote the acquisition of some of the basic skills involved in choice-making may have been missed or reduced (Olney & Salomone, 1992).

Choice-making skills may therefore need to be approached as a specific training target rather than simply as a permissible behaviour (Tymchuk, Andron & Rahbar, 1988). To this end, Williams (1991) suggested that in order to exercise at least some control over daily living, individuals should be given the chance, training, technology, respect and encouragement to do so.

Shaddock, Zilber, Guggenheimer, Dowse, Bennett and Browne (1993) also advocate the need for more extensive and thorough training for support workers. This training needs to be backed by appropriate research and evaluation in order to meet current policy requirements.

According to Parsons and Reid (1990) more specific procedures for providing choice-making opportunities are required. The impaired motor and communication skills of persons with severe disabilities can prohibit the expression of preferences in the manner typically used by others, so Landesman-Dwyer (1981) described a number of possible approaches to develop greater freedom of choice. These included more money, more support workers, smaller programmes, greater family and community involvement, more normalised learning opportunities, and increased training for support workers and residents. All but training approaches are beyond the scope of this thesis.

At present there are very few guidelines or widely run programmes aimed at teaching choice-making skills directly to people with intellectual disabilities. This is partially due to the problems of individual differences and the need for the training of each resident to vary according to skill levels and abilities. This lack may be artificially and unnecessarily limiting choices available to people with intellectual disabilities.

PLANNING TRAINING

In order to develop training in choice-making skills, a detailed sequence of the behaviours to be learnt need to be identified. Following analysis of the relevant skills, the next step is to assess the current development of those skills, and examine how the characteristics of the individual and the environmental contribute to that development. The information obtained can then be used to determine the instructional

techniques and devices that will lead to successful acquisition of the target skills. Any approach to training then needs to be evaluated in order for service delivery to be based on valid research. The first stage in the development of training, analysis of the skills involved in choice-making, will be examined in this chapter, while the remaining stages of the development process will be discussed in subsequent chapters.

MODELS OF CHOICE-MAKING

According to the dictionary, choice means to "decide between alternatives". This is a rather simplistic definition and many have attempted to more fully describe the concept. Choice is the ability to actively select among two or more alternative conditions. It is based on prior experiences, present needs, and future goals.

There are a number of approaches to describing choice-making. Some involve formal decision-making models where options are objectively weighed and the best one is selected. One such model was proposed by Tymchuk, Andron, and Rahbar, (1988). The model consisted of six decision-making components: (1) identifying that a decision needs to be made, (2) what the goal would achieve, (3) who should make the decision, (4) what alternatives there are, (5) the consequences of each alternative, and (6) selection between alternatives. Other approaches involve hierarchies of choice-making skills, from simple preference, to choice as a decision-making process, through to choice as an expression of autonomy and dignity (Houghton, Bronicki & Guess, 1987).

Another approach to decision-making, used in a study by Jenkinson and Nelms (1994), was to define three strategies for making choices. These were defensive avoidance (procrastination and rationalisation), hypervigilance (hasty selection to avoid immediate tension regardless of consequences), and vigilance (systematic and objective evaluation of alternatives). The study demonstrates that people with and without a disability both tend to use the first strategy. This confirms that decision-making is not necessarily an entirely rational process, and thus expecting people with an intellectual disability to always use the objective vigilance strategy is unrealistic. There were, however, more defensive

avoidance responses and fewer hypervigilant or vigilant responses for the group with a disability than those without, suggesting that encouraging vigilant responses, although not essential, may be useful.

Ideal decision-making also requires not just the desirability of an outcome, but also the probability of the selected option occurring (Jenkinson, 1993). Rational approaches to decision-making do not take into account factors such as limited attention span, anxiety, shifting values, disappointments and regrets, which affect our judgements of both the desirability and the probability of a given outcome. Emotional reactions are more likely to occur in complex decisions involving large numbers of options or uncertain outcomes, while clear preferences are most likely when the choice is familiar, simple and directly experienced (Jenkinson, 1993).

An alternative approach is to view choice-making in terms of a complex array of behaviours rather than a single skill. The model used in this thesis is based on a third approach to describing choice-making, developed by the Advancing Choice Project headed by Professor Tony Shaddock. This approach groups choice-making behaviours into three basic stages: *Option Recognition*, *Evaluation and Selection*, and *Acting on the Selection,* each of which encompasses an array of skills (Zilber, Rawlings & Shaddock, 1994)

Support workers have been identified as one of the major determinants of the opportunities for choice for people with intellectual disabilities, but they are often not trained in identifying choice-making opportunities and do not know how to incorporate choice into all aspects of residents' lives (Shaddock, Zilber, Guggenheimer, Dowse, Bennett & Browne, 1993). This may result in them leaving out choices they consider inappropriate, or finding it more expedient to anticipate preferences and make decisions rather than go to the effort of presenting choices in an appropriate manner.

It is therefore important to examine choice behaviours not just in terms of resident skills and behaviour, but also with regard to support worker behaviour that promotes or interferes with resident choice-making.

CHOICE-MAKING STAGES

Stage A: Option Recognition

The skills involved in the *option recognition* stage are: identifying a choice opportunity through recognition that options exist; the ability to discriminate between those options; and awareness that selecting one of those options will have an impact on the outcome. Some of the factors which determine the complexity of this task include: how easy it is to discriminate between the options; the form of communication used; how complex the choice is in terms of number and type of options; how much time is allowed; and how much information is available. The skills involved in *option recognition* are more fully described below.

Awareness of Influence

The first skill required for choice-making is the ability to identify when there is an opportunity for input. Experience with making choices in the past is an important requirement of choice-making, without it the individual is likely to be unaware that they can influence the outcome of a situation. Learned helplessness is a major hurdle to be overcome in the development of choice-making skills (Jenkinson, 1993). Support workers can help to overcome this through encouragement, support, emphasising the existence of an opportunity, and waiting for a response.

Form of Communication

Identification and recognition of the specific options available to choose from depends on the way in which they are presented. This may involve understanding a word or a gesture, or being familiar with a symbol such as: a picture, an abstract representation of an activity, or the packaging of the object being offered. It requires being able to distinguish between the actual option and whatever is used to represent it.

It is often up to the support worker to identify the best means of presenting the options to each resident. Inappropriate forms of presentation may be one of the greatest impediments to choice-making, as the best means of presentation is determined by an individual's communication skills and experience. The simplest representation of the choice is the object itself, and choices become more difficult when there

are no physical cues to indicate the nature of the option being offered. Sampling may also be used to aid understanding of options prior to choice. The best approach is to use communication forms already developed rather than attempt to train new ones (Berg, Wacker, Ebbers, Wiggins, Fowler & Wilkes, 1995).

Verbal Communication

Relying solely on verbal communication with people with an intellectual disability is fraught with risk. They are especially likely to give biased answers that are influenced by question structure and wording (Sigelman, Budd, Spanhel & Schoenrock, 1981; March, 1992). Yes-no questions are answerable by most people with an intellectual disability but tend to yield invalid answers, as individuals consistently respond 'yes' or 'no' regardless of the options offered. The rates of acquiescence tend to be very high and negatively correlated with IQ.

Either-or questions are slightly more difficult to answer but yield more valid responses although they can result in a systematic bias for the latter of two options (Sigelman, Budd, Spanhel & Schoenrock, 1981). This type of questioning however, has proved to be less affected by bias than yes-no formats.

Non-Verbal Communication

Real objects or pictures, either illustrations or photographs, may be more reliable than verbal forms of presentation as these facilitate understanding of question content and increase responsiveness. Objects and pictures can increase understanding by providing additional information to cue an option, and reduction of short-term memory requirements. However, any symbolic representation of options requires familiarity and needs to be as concrete as possible.

Alternatives to verbal communication can reduce the tendency for response biases by reducing the reliance on memory and presenting options in a non-hierarchical manner. Sigelman and Budd (1986) found that, although pictures had no impact on reducing a tendency toward acquiescence when used as an adjunct to yes-no questions, they did improve responsiveness to multiple-choice and either-or questions.

Responsiveness and intelligibility can be enhanced by reducing the demands on expressive verbal abilities by allowing nonverbal responding such as gesture or pointing to a photo or object (March, 1992). Photographs are useful in improving responsiveness, as they: increase the frequency of responses; move the focus of the interview away from the participant to the photographs; add objects of interest; increase the number of spontaneous comments, gestures and signs; increase intelligibility of answers; and increase comprehension. In low-verbal individuals, pictures also tend to reduce a bias toward choosing the last of two options, and may be helpful as an aid to interviewing individuals who have verbal limitations. However, pointing may indicate recognition rather than preference (Jenkinson, 1993).

When residents do not respond to choice opportunities, it may be necessary for support workers to make some tentative thoughtful guesses and see what works (Lovett, 1991). The resident's non-verbal communication can then be interpreted as an indirect indication of choice by gauging the success or otherwise of the guesses. This fits with the assumption that all behaviour has a function and that challenging behaviour can be a means of communication. One way of identifying whether lack of response, or non-compliance is a choice not to participate is to develop the use of a symbol which indicates selection of none of the options offered (Nozaki & Mochizuki, 1995).

Complexity of Choice

The complexity of choices available to those with a disability is determined by the experience of the individual, but is influenced by the discriminability of the options, the number of options available, the information provided, and the time available for processing. When presenting choices the support worker needs to find a balance between overwhelming the resident and unnecessarily limiting the choice. The aim should also be to rather gradually build up skills by carefully increasing the complexity of the choice.

Discriminability

The more alike options are, the harder it is to discriminate between them, and the more difficult the choice is to make. Options such as chocolate cake and brussel sprouts are quite different and are much easier to discriminate between, and thus choose between, than chocolate cake and chocolate biscuits. The skills involved in discriminating between options require both experience and sensory development.

Number of Options

In addition to discriminability, the number of options available determines the complexity of the choice. Whether or not these options need to be specified in the presentation of choice will depend on the ability and experience of the individual resident. To determine this, the support worker needs to be familiar with the resident's capabilities.

More options may appear to offer greater freedom of choice, but may overwhelm the individual, while too few options may unnecessarily limit the choice if the resident is unable to suggest alternatives. Open-ended questions are an alternative, *(eg. what would you like to drink?)*, but some individuals will not be able to generate options for themselves or may not have sufficiently developed verbal skills to make open-ended questions practical as they require representations of specific options in order to make a response (March, 1992).

Closed options can lead to the problem that the individual does not want any of the options offered, or may result in response biases depending on the order of presentation. It is also important that all options offered are available and acceptable, for without this there is no real choice.

Information

The information provided regarding a choice can affect the decision-making process by influencing the ease of comprehension and the difficulty of the choice. Decision-making may depend on whether alternative courses of action are made explicit. Ideally, learning to make choices also involves learning how to seek out relevant information (Jenkinson & Nelms, 1994). In the meantime the choice can be enhanced

by always qualifying questions with information. This may mean drawing attention to the possibility of choosing none of the options, as well as the option to stop, and indicating that choices can include alternative means as well as choice of activity. Support workers can also encourage residents to exercise initiative and include other options and opportunities themselves. However, support workers need to ensure that the information they are providing is enhancing understanding and not overwhelming the decision-maker.

Time Requirements and Concepts

People with intellectual disabilities may require more time to process information in order to identify or recognise the options available and make a choice. Therefore, the greater the time pressure, the greater the demands on processing capacity, and the more complex the choice.

The concept of immediate reward and delayed gratification is a very complex one, *(eg. buy a magazine now or a new CD next month)* and choices dependent on understanding of this concept may only be appropriate for those with more developed skills.

Stage B: Evaluation And Selection

After *option recognition*, comes the second stage of choice-making - *evaluation and selection.* This consists of a propensity toward one option over another, and a method of indicating that propensity. Another skill that can be involved is the ability to identify and evaluate the consequences of the various options. Although consideration of consequences is important for informed decision-making, it is not a requirement of choice-making per se, as we all make choices at times that are impulsive and not in our best interests.

Developing Preferences

If we accept that "choosing" is the act of an individual selecting a preferred alternative from among several familiar options, then individuals need to learn to identify personal preferences for themselves. Despite limited opportunities for learning the skills involved in choice-making, many individuals with an intellectual disability have been found to be very

accurate in ranking the order of their needs, although they may be poor in the use of absolute ratings (Brown, Bayer & Brown, 1988).

Parsons and Reid (1990) also showed that preferences were highly individualised and that the preferred item was selected on the majority of trials. Furthermore, responses changed over time, suggesting the development of new preferences.

However, it is very difficult to select an option if you have no experience of what the options actually are. This is an important consideration for people whose life experience has historically been fairly limited. In order for an informed choice to be made it may be useful to provide opportunities for sampling or more information about the options in order to facilitate selection.

Evaluation of Consequences

Although evaluation of consequences is not essential for choice-making, it is a reason often given for the denial of choice to those who are deemed to lack the skill. Support workers can help the resident to develop this skill by modelling identification and consideration of consequences.

Responsibility

Choice and decision-making involve responsibility and an element of risk, and residents should be taught how to exercise their right to choose responsibly (Goode & Gaddy, 1976). Like anyone else, people with an intellectual disability need to learn that poor choices sometimes have unpleasant consequences. People fail to learn if not exposed to risk, and denial of choice, based on the possibility of future inappropriate actions, is inconsistent with individual rights (Guess, Benson & Siegel-Causey, 1985).

Most people, in the normal development of skills, make a wide range of mistakes and experience trial and error, but many individuals with a disability are not allowed to make mistakes since these are seen as a sign of disability, not as a sign of learning (Brown, 1988). Some people with intellectual disabilities will make poor choices that could jeopardise the safety and well being of themselves or others, but those without a disability can also act in undesirable ways.

Ideally, decisions are made to best help us achieve our goals by considering the desirability of an outcome and the likelihood of it occurring, and choosing a course of action to maximise the likelihood of achieving our goals (Jenkinson, 1993). This, however, is not always the case as we can base decisions on very subjective and irrational criteria, and decisions can be incompatible with each other. Choice-making often deviates from the ideal model of decision-making by choosing the first option that appears satisfactory, eliminating options on the basis of a single attribute or consequence, or by yielding to the influence of factors that are irrelevant (Jenkinson & Nelms, 1994).

Denial of the choices of people with intellectual disabilities because they tend to make decisions based on their own experiences rather than by deliberating on possible alternatives and their consequences (Jenkinson & Nelms, 1994), is therefore not consistent with them having the same opportunities as other members of the community.

Some even consider that to choose unproductive and unsafe activities is the right of all people, and should be available to people with intellectual disabilities as long as they can demonstrate understanding of the consequences (Bannerman, Sheldon, Sherman & Harchik, 1990). However, at times, society may compel any of us to meet the contingencies required to sustain our lives, regardless of personal choice and our ability to identify consequences. An example of this is the legal requirement for the wearing of seatbelts. Thus, there is a precedent in the general community for overriding choice in the name of safety.

Duty of Care

Support workers are often faced with the problem of balancing their duty of care towards residents with the principle of encouraging autonomy and independence (Shaddock, Zilber, Guggenheimer, Dowse, Bennett & Browne, 1993). Residents may need assistance to recognise consequences but while learning they should be encouraged to make as many choices as their abilities allow as long as these are not significantly detrimental to the resident or to others (Bannerman, Sheldon, Sherman & Harchik, 1990).

"Dignity of risk" is the right to exercise personal initiative, to have the opportunity to understand the consequences of personal decision-making, and learn from mistakes. The goal of this is to prepare an individual to function effectively without ongoing assistance (Shevin & Klein, 1984). However, support workers face the difficulty of weighing the value of freedom of choice and the hope that the resident will learn from a mistake and make a different choice next time, against the negative consequences of an unwise or ill-informed choice. Thus the support worker's "duty of care" may compete with the resident's "dignity of risk".

Although support workers must consider their duty of care, choices about aspects of daily living usually need not be interfered with. Residents were found to agree with basic management such as washing hair regularly, dressing neatly, and keeping rooms clean and tidy but were evenly divided between yes and no regarding issues about being allowed to smoke and having someone look after your money (Elks & West, 1982). In general, the majority of residents in Elks and West's study responded with a consistent picture of a model, but nevertheless normal citizen, although they may have been giving desirable responses rather than accurately reflecting their attitudes.

In practice, support workers sometimes feel justified in overriding residents' preferences, particularly when residents fail to understand the negative consequences (Stancliffe, 1991). Overtly or covertly overruling resident decisions or preferences may occur because of financial, health, or safety implications. The conflict between choice and duty of care may result in artificial limits being placed on the choices of adults with intellectual disability (Shaddock, Zilber, Guggenheimer, Dowse, Bennett & Browne, 1993).

When support workers perceive that "duty of care" necessitates intervention it is best if they explain their reason in language suited to the individual rather than simply overriding the choice. This maximises the chance of the resident learning from the experience rather than simply becoming confused and experiencing choice as negative.

Communication of a Selection

The final step of the *evaluation and selection* stage of a choice involves effective communication of that selection. Communication problems can result not only from reduced cognitive competence, restrictions in vocabulary and verbal fluency, but by support workers not being aware or acknowledging resident expressions of choice.

Communication Problems

As people with an intellectual disability may not use standard methods for communicating their preferences, support workers must be aware of alternative communication modes. Communication difficulties can occur because people with intellectual disabilities and support workers use quite different behaviours for communicating (Houghton, Bronicki & Guess, 1987).

Support workers need to use observation as well as inferential and empathic capacities. Shaddock, Zilber, Guggenheimer, Dowse, Bennett and Browne (1993) found that support workers were not always able to judge the communicative intent of behaviour and tended to focus on controlling the person's behaviour directly, rather than viewing challenging behaviour as a form of communication. Emotion may communicate enjoyment or not in the activity or object, and seeking or avoiding an activity may be an indication of choice through direct action.

Acknowledging Communication

Houghton, Bronicki and Guess (1987) found that self-initiated expressions of preference by children with severe disabilities were responded to by support workers at extremely low rates. Both verbal and non-verbal indications of preference should be acknowledged in order to build independence, choice, and control into the daily activities and routines of every person. This can help overcome the earlier lack of access to the opportunities necessary for developing the capacity to choose and to have those choices be the determinants of one's actions (Wehmeyer, 1992). Support workers should also emphasise that a choice has been made and elicit feedback about whether the choice is liked (Shevin & Klein, 1984). As discussed earlier, concrete representations of

options can help facilitate resident responses through action or pointing as well as increasing the chances of an informed choice.

Stage C: Acting On The Selection

The experience is not a real opportunity for choice unless the selection of an option has an impact on the environment. The third and final stage of making a choice, *acting on the selection,* is dependent on having the means to follow-through with the selected option, either personally, or gaining the appropriate assistance of others (Guess, Benson & Siegel-Causey, 1985).

Reinforcement

Once the choice has been communicated and recognised it needs to be reinforced. Choices are reinforced most effectively when a response is reacted to immediately and frequently (Cullen, 1999), and there is a clear connection between response and receiving the preferred option.

Acknowledgement

It is important for support workers to acknowledge expressions of choice by residents. This helps the resident to establish a causative link between their response and any subsequent outcome. Acknowledgment also confirms that the support worker has understood the resident's response. In a study of classroom settings, Houghton, Bronicki and Guess (1987) found that although students with severe intellectual disabilities expressed preferences at quite a high rate (90% of observations), teachers responded to only 15% of these. This is likely to be extremely detrimental to the development of a sense of control, particularly as the students relied on the teachers to help them follow-through with the choice.

Follow-Through

The choice needs to be followed through, or an appropriate reason given if this is not possible, in order for the individual to establish a connection between their choice and an impact on their environment. When a choice is honoured it can result in feeling empowered. This is an important step in developing self-confidence and self-respect. Lack of

influence over many aspects of their lives can result in a lack of positive self image and a sense of inadequacy. Learned helplessness may result, leading to withdrawal, which compounds an individual's existing disability making it appear even more severe (Dattilo & Rusch, 1985).

Encouragement

Support workers need to be aware that it will take time to overcome past feelings of powerlessness. Sometimes people will not want to make choices and will want others to decide for them. Encouragement and consistent responses to expressions of preference and choice are essential in order to encourage future choice-making.

Effort

Choice-making skills are also more likely to be established and developed when less effort is required from both the residents and the support workers (Cullen, 1999). If too much effort is required to offer, respond to, or follow-through with choices then the reinforcement experienced may be reduced and choice opportunities may be missed or dismissed as too difficult. One of the ways to overcome this is to emphasise the benefits so that these outweigh any costs associated with promoting choice.

Additional Skills

The skills described in each of the choice stages do not operate in a vacuum, and many other skills may be required in order to support choice-making skills.

Assertiveness training, building of positive self-image and dealing with emotional concerns, promote the ability of the individual to control programme goals that in turn increase self esteem. Counsellors can play a part in helping those with intellectual disabilities to cope with their worries and concerns (Brown, Bayer & MacFarlane, 1989).

Anxiety management in novel situations, and the development of skills to manage emotions such as frustration, impatience and disappointment may also be useful skills in supporting choice-making behaviours (Wehmeyer, 1992).

Other useful skills include the ability to identify and solve problems associated with gaining the chosen option. Making choices may also require skills associated with independence of thought, following through with a task, dependability, self-confidence, and willingness to admit mistakes (Shaddock, Zilber, Guggenheimer, Dowse, Bennett & Browne, 1993). Understanding the differences between immediate and delayed gratification of desires, and the ability to plan for future choices are also important skills. Lack of any of these skills, or other more specific skills such as money management and independent travel, can limit access to free choice (Stancliffe, 1991).

SUMMARY

People with severe intellectual disabilities have generally not received the same opportunities to learn choice-making skills as others. Developing choice-making involves lifelong experiences and instruction (Wehmeyer, 1992) so intensive teaching may be required in order for people with an intellectual disability to overcome previous lack of experience and adequately develop the skills involved in making choices.

In order to develop an effective training approach to teach choice-making skills to adults with intellectual disabilities, a comprehensive description of the components involved is required. The three stages of choice-making: *option recognition*, *evaluation and selection*, and *acting on the selection* were used as a basis for that description. The description examined the skills and behaviours of both residents and support workers, as both need to be taken into account in any assessment or intervention for choice-making behaviours of adults with an intellectual disability.

Chapter Six

STUDY ONE - PRELIMINARY SURVEY

INTRODUCTION

The next step in developing training to teach choice-making, following the analysis of the skills involved, is to assess the current extent of development of those skills. However, before this can be carried out, an appropriate assessment instrument needs to be developed. This requires the identification of relevant aspects of choice behaviour to examine, as well as appropriate choice areas to focus on.

The primary purpose of Study One and Study Two is to answer the first of the key questions of this thesis: how can choice be measured? This initial study describes the survey of a small sample of support workers in order to determine which daily choice areas they considered to be the most important for residents with intellectual disabilities. An additional purpose of the survey was to collect information to gauge support workers' perceptions regarding what prevented residents from making choices in daily-living areas, and what was necessary to improve both the choice opportunities available, and the skills of the residents that they worked with. This information could then be used to help identify appropriate skills for the assessment instrument to examine, and to provide a foundation for the development of training strategies.

METHOD

Materials

The initial survey (Appendix 1) consisted of thirteen questions. The first part of the survey was intended to collect information on the general experience and training of the support worker respondents. The remainder of the survey gauges support worker perceptions regarding: the areas of daily living most important to people with an intellectual disability;

the things which prevent choice; and what can be done to improve the opportunities for choice and the abilities of residents to make choices. For each of the latter questions support workers were asked to list a number of answers which were then scored according to frequency of each response and priority determined by the order of response, with higher scores the earlier the responses were listed.

Procedures

The survey was distributed to approximately 50 employees of a single residential support service in southern Tasmania that provided accommodation and support to twelve adults with an intellectual disability, in three separate houses. This service was considered to be representative of services in the region and was selected as it provided services to residents with a range of degrees of intellectual disability. Participants were informed that their responses were confidential, anonymous and voluntary.

Respondents

Of the surveys distributed, twenty-one completed forms were returned. The support workers who completed the forms had an average of 43 months experience in the disability field, ranging from five months to fourteen years, and had spent between six weeks and nineteen months working in their current residence (average of seven months). Sixty-two percent (13 respondents) had undertaken formal training in the area of intellectual disability. Twenty-nine percent (6 respondents) had attended a Disability Services workshop on choice-making and all but one had found it useful. Seventy-nine percent (11 of the 14 that completed the question) indicated that they would find further training in choice-making useful, while two of the remaining three were unsure and only one said they would not find it useful. Support worker characteristics are shown in Table 6.1.

Table 6.1: Summary of support worker experience and training (n=21).

	EXPERIENCE		TRAINING			
RESPONDENT	1. Time in Current Residence (months)	2. Time Working in Disability Field (months)	3. Formal Training in Disability Field	4. Attended a Choice Workshop	4c). Found Workshop Useful	5. Interested in Further Choice Training
1	12	60	BA (Psych), partial Intro to Developmental Disability - TAFE	no		
2	5	12	Advanced Certificate in ID	yes	yes	yes
3	19	25		yes	no	yes
4	3	50	Disability workshops	no		
5	3	36		no	yes	
6	4	54	Intro. to Developmental Disability - TAFE	yes	yes	yes
7	5	12	BA (Hons.) Psych, M Psych	no		
8	7	19	Intro. to Developmental Disability - TAFE	yes	yes	yes
9	3	72	Skillshare	no		maybe
10	8	132	nil	no		yes
11	18	18	partial BA.	no		
12	4	38		yes	yes	yes
13	17	17	Advanced Certificate in Developmental Disability - TAFE	no		yes
14	10	96	B. Social Science (Psych/Soc.), Advanced Certificate in Welfare Studies	no		yes
15	3	168	Degree	yes	yes	maybe
16	2	9	Graduate Diploma of Special Education	no		
17	10	60	Intro to Developmental Disability - TAFE	no		yes
18	3	5	partial Advanced Certificate in Developmental Disability - TAFE	no		yes
19	1.5	7		no		yes
20	7	7	none	no		
21	8	8	none	no		no
Average	**7.26**	**43.10**				
SD	**5.34**	**43.91**				
Percentage			**64.71%**	**28.57%**	**85.71%**	**78.57%**

RESULTS

Daily Choice Areas

Table 6.2 outlines the responses to questions 7 and 8, about the areas of daily living that the support workers felt were the most important for people with intellectual disabilities. Responses were allocated to one of twelve general choice areas, and the most frequent areas of choice were those involving *food*, *leisure*, *clothing*, *day placement*, and *hygiene*. The responses of each support worker were assigned ranking scores indicating the importance attributed to the choice area. The most important, that completed at question 7i), was assigned a score of 6, the next at 7ii), received a score of 5, and so on to the least important area of daily living at 8iii), which received a score of 1. Scores were assigned according to where the responses were entered regardless of how many responses were completed.

Support workers were also requested to indicate whether the residents were currently making choices in the areas they indicated (question 9). The percentage of support workers indicating that current choice was available in the area, out of those that completed the question, is indicated in the final column of Table 6.2. It is evident that although these were the most important areas, residents did not currently always make these choices.

Table 6.2: Support worker perception of the most important *daily-living areas* for choice-making.

CHOICES	RESPONSES	NO.	SCORE	% CHOICE
Food	Food (5), Food choices (4), Diet (3), Meals (2), What they would like to eat (2), Choice in food/diet, Menu for meals, Grocery shopping, Food and food preparation, What they eat and when they eat, Choice of what time for meals	22	102	81.25% (of 72.7%)
Leisure	Activity choices (4), Leisure activities (3), Activities (2), Recreation and leisure (2), Activities - what/when/how/where, What they do in leisure time, Activities/leisure time, What they would like to do with the day, Choice in whether residents go out or not, Outings, Entertainment, Travel, Hobbies	20	91	64.29% (of 70%)
Clothes	Clothing (7), Clothing choices (3), Clothes (2), Selection of clothing, Choice in clothes/appearance, What they wear and buying new clothes, dressing, Fashion	17	70	90.91% (of 64.7%)
Day Placement	Day placement activities (2), Day placement and support, Work or stay home, How many days per week at day support, What work activities they are engaged in, Programme motivations, Work or occupational therapy, Work options, Work placement, Occupational programming, For older residents the age at which they retire	12	41	0% (of 75%)
Hygiene	Bathing (2), Hygiene, Personal hygiene, Which staff to assist with bathroom, Personal care, Hair style	7	27	100% (of 42.9%)
Who to live with	Who they want to share a house with, Who they prefer to live with, Who they live with, Who they want to live with, People they live with, With whom they live	6	20	25% (of 66.7%)
Relationships / Family	Personal relationships, Social network, Sexuality, Family	4	11	25% (of 100%)
Chores	Household chores, Chores around the home, Housework, Household responsibilities	4	10	100% (of 75%)
Money	How they spend their pension, Ability to access money, Shopping	3	9	66.67% (of 100%)
Staff	Which staff will assist them, Ability to select support staff, Staff they would like to work in the house	3	8	50% (of 66.7%)
Where to live	Where they would like to live, Where they live	2	4	0% (of 50%)
Other	Independency and freedom, Time to get up and go to bed, Doctor/dentist, Management of services, Respect for other residents	5	14	40% (of 100%)

Notes: 'No.' refers to the number of times the 'Choice Area' category was indicated by support workers; when more than one support worker made the same specific response (column two), the frequency is indicated by the number in brackets following that response.

'Score' is the number of times the 'Choice Area' category was indicated multiplied by the score assigned to the position the response was made at, ie. response at 7i)=6, 7ii)=5, 7iii)=4, 8i)=3, 8ii)=2, and 8iii)=1, on the preliminary survey.

'% Choice' is the percentage of support workers who indicated that residents were currently making choices in the indicated area, while the percentage in brackets indicates the proportion of support workers who indicated the choice area and marked whether or not current choices were made.

Limitations on Choice

The next question in the survey, question 10, was intended to gauge support worker perceptions about the sorts of things that prevent residents from making choices in daily-living areas. Responses were grouped into ten broad categories. These categories, the number of times a response fitted the category, and a ranking score based on the priority given to the response, i.e. the first and most important limitation at 10i) was allocated a score of 3, down to the least important limitation at 10iii), are presented in Table 6.3. Again, scores were assigned according to

where the responses were written, regardless of how many responses were completed.

The areas that support workers thought most prevented residents from making choices in daily-living areas were *limited resources*, *communication difficulties*, *lack of time*, *disability of the resident*, *management structures*, and *support workers not offering options.*

Table 6.3: Support worker responses to the question of what *prevents* residents from making daily-living choices.

LIMITATIONS	RESPONSES	NO.	SCORE
Limited resources	Not always enough staff to assist one to one, Lack of staff, funding (2), Transport (2), Finance, limited income, funding bodies, Practical/external restrictions (eg. occ. support), Resources (clients money, staffing time), Outside influences and needs, Obligations	13	28
Communication difficulties	Communication, Communication techniques used, Lack of communication, Nonverbal, Lack of verbal skills, Unable to communicate their feelings, Communication approaches which aren't always compatible with client's level of understanding, Communication and confidence, Being non-verbal	9	20
Lack of time	Lack of time (3), Limited staff time, Time frames, Time	6	15
Disability	Lack of knowledge, Level of functioning of residents, Too intellectually impaired, Disability of client, Comprehension abilities of client, Ability	6	14
Management structures	Programme hasn't made allowances, Dept of Community Services, Bureaucracy, House routine is not flexible enough, Policies of management, CIP structure at present	6	12
Support workers not offering options	Staff offering options, Staff making choices, Wrong perception of who should do things (staff or client), Staff don't even bother to ask, Not given choices	5	11
Lack of resident experience	Years of institutional living (learned dependence), Lack of knowledge, Learning/practice	3	5
Lack of empowerment	Lack of motivation, Clients feeling empowered to make choices	2	3
Limited staff knowledge	Staff recognising client's preferences, Support workers not really knowing clients	2	3
Group living	Fit in with other residents	1	2

Notes: 'No.' refers to the number of times the 'Limitation' category was indicated by support workers; when more than one support worker made the same specific response (column two), the frequency is indicated by the number in brackets following that response.

'Score' is the number of times the 'Limitation' category was indicated multiplied by the score assigned to the position the response was made at, ie. response at 10i)=3, 10ii)=2, and 10iii)=1, on the preliminary survey.

Improving Opportunities for Choice

The final two questions were designed to assess the opinions of support workers regarding what could be done to improve the opportunities for choice-making, question 11, and the abilities of the residents with whom they work, question 12. The categories of responses regarding choice-making opportunities are presented in Table 6.4, again

with the frequency of the response, and the ranking score based on the order of response. The response indicated at 11i) was assigned a score of 3, while a response made at 11iii) was given a score of 1. As in the previous two sections, scores were assigned according to where the responses were recorded, regardless of how many responses were completed.

The most frequent responses categories identified were *offer choices*, *communication/aids*, *resources*, *staff awareness*, and *resident training*.

Table 6.4: Support worker responses to what could be done to improve *opportunities* for daily choice-making.

IMPROVE OPPORTUNITIES	RESPONSES	NO.	SCORE
Offer choices	Offer choices, Actually give a choice, Follow consistent routine in giving opportunities, Consistently providing choices, Staff awareness of offering choices, Let them have more say, Explore more options	7	15
Communication / Aids	Enable a clear picture of the options, Photographic choices, Individual mechanisms or systems to aid clients (clients have individual abilities and needs), Compic, Using real objects, Photos	6	16
Resources	Having a housekeeper to attend to chores, More staff, Money, Reduce outside influences and needs	4	10
Staff Awareness	Make staff aware of choices to be made, Co-ordinate all staff, Appropriate reflection of staff to client needs, Get to know clients well	4	9
Resident training	Focus on one area of choice-making at a time, Teach them how to make choices, Education - explanations of possible choices, Support staff to spend more time with residents building skills	4	9
Empowerment / Encouragement	Independent advocacy, Encouragement and self esteem, Empowerment	3	8
Staff training	Staff training, Staff training relative to clients being supported, Training of staff	3	5
Flexibility of management structures	Increase flexibility of funding/day placement/type of residential accommodation, Flexible house routines	2	5
Consequences	Improved opportunities to make consequences stick, Be prepared to take educated risks	2	2
Time	More time, Structure shift to enable time and support to make choices	2	5
Group living	Fewer residents per house	1	2
Experience	Exposure to experience of choice for clients	1	1

Notes: 'No.' refers to the number of times the 'Improve Opportunities' category was indicated by support workers.

'Score' is the number of times the 'Improve Opportunities' category was indicated multiplied by the score assigned to the position the response was made at, ie. response at 11i)=3, 11ii)=2, and 11iii)=1, on the preliminary survey.

Improving Ability to Make Choices

The categories of responses regarding improving the choice-making abilities of residents are presented in Table 6.5, again with the frequency of the response and the ranking score based on the order of response. In this case the response indicated at 12i) was assigned a score of 3, while if a response was made at 12ii) it was scored at 2, and at 12iii) scored 1, regardless of how many responses were made.

The most frequent response categories were in the areas of *offer choices*, *empowerment/encouragement*, *communication/aids*, *experience*, and *resident training.*

Table 6.5: Support worker responses to the question about what can be done to improve resident *abilities* to make choices.

IMPROVE ABILITIES	RESPONSES	NO.	SCORE
Offer choices	Make sure the residents are given a choice in everything they do, Constantly asking residents for their choices, Making clients aware that they have choices, Offer them choices, Structure routines for participation and choice, Practice, Participation	7	20
Empowerment / Encouragement	Empowerment, Model and encourage choice-making, Lots of verbal assistance and praise, Encouraging them to verbalise or symbolise their choices, Staff to encourage choice-making, Encouraging choice-making with simple things to start off with and expanding them, Make sure they will enjoy it	7	14
Communication / Aids	Different ways to indicate their individual needs, Use choice systems suitable to particular client, Using other resources (samples, photos), Implement a range of communication models (photo catalogue of activities), Communication skills, Picture choices	6	14
Experience	Providing opportunities to try new things, Experience of consequences, Expand their experience and knowledge, Access to more varied residential types, day placements, etc.	4	10
Resident training	Training (consistent), Teaching residents that there are choices they can choose from, Keep teaching within their scope	3	8
Staff training	Staff training in how to present the options to specific clients, Educational programming throughout the services	2	6
Time	Time, Maybe more time spent individually	2	6
Involvement in management	Resident house committee, Resident participation with NGO structures	2	3
Assessment	Psychological assessment to find out how and if clients can make appropriate choices	1	1

Notes: 'No.' refers to the number of times the 'Improve Abilities' category was indicated by support workers.
'Score' is the number of times the 'Improve Abilities' category was indicated multiplied by the score assigned to the position the response was made at, ie. response at 12i)=3, 12ii)=2, and 12iii)=1, on the preliminary survey.

DISCUSSION

Daily Choice Areas

The focus of each of the studies in this thesis is on daily choice areas. The rationale for this is firstly, that making choices in these areas has been found to play a significant role in quality of life and is consistent with the principles of normalisation. Secondly, daily choices, by definition, come up frequently and provide a greater number of practice opportunities, which is essential for skill acquisition, and a larger number of opportunities to measure change. Thirdly, they are expected to be simpler, more concrete choices to make, and thus the foundation for developing choices in more major life areas. Finally, changing practices in these areas should be within the domain of individual support workers and residents, and need not require any major administrative or management involvement.

As a consequence of the focus on daily choices in group homes, the decision was made to exclude the area of day placement choices despite it being rated by support workers as the third most important area (Table 6.2). Choices regarding day placements either do not occur on a daily basis, do not involve residential support workers, or do not occur in the group home. Therefore, the four areas of daily living to be focussed on in the remainder of this thesis are *food*, *leisure*, *clothing*, and *hygiene* choices. These were also four of the five top areas of choice identified by Shaddock, Zilber, Guggenheimer, Dowse, Bennett and Browne (1993) in their survey of choices in day programmes for adults with intellectual disabilities, the fifth area in their study was shopping. Furthermore, Lancioni, O'Reilly and Emerson (1996) suggested that very similar daily-living areas were non-controversial and appropriate for developing choice skills without risking dangerous options, and McKnight and Kearney (2001) described leisure, eating and personal hygiene as some of the most important home-based activities.

In the final two studies, the contribution of *chores* involvement is also examined, although not as a choice area. The areas of *who to live*

with and *relationships/family* were excluded as they are considered to be major life decisions and outside the scope of this thesis.

Despite the four targeted daily choice areas being recognised as important to quality of life, and relatively simple concrete choices to make, it was evident from this preliminary study, despite a relatively small sample group and low response rate, that residents were not always making choices in three of the four areas. The only exception, according to this sample, was in the area of hygiene choices. These results suggest that there is scope for improving the choice-making of adults with intellectual disabilities even in these most basic of areas. The high rate of hygiene choice may be indicative of the importance of this area to independence and quality of life.

Limitations on Choice

When support workers were asked to identify some of the things that prevented residents from making choices in these basic areas (Table 6.3), their responses fell into two basic categories: those within their control to change, and those outside their control. Those, at least partially, within their control were things such as *communication difficulties*, *lack of time*, *support workers not offering options, lack of resident experience, lack of empowerment* and *limited staff knowledge*. In each of these areas there is potential for reducing the limitations on the choice-making of adults with intellectual disabilities. One of the biggest hurdles though, is for support workers to recognise and utilise this potential by doing things such as making use of alternative communication systems, prioritising their time, increasing resident experience of choice by offering more choice, and developing their own skills and knowledge about how best to promote the choice-making of the people that they work with.

Even the impact of the areas outside the control of the support workers, such as *limited resources*, *disability of the resident*, and *management structures* may be reduced or worked around. Although the disability level of an individual resident is beyond the control of the support worker to a large extent, the support worker does have a considerable amount of influence over the degree of functional disability that is

expressed. If the support worker assumes that the resident is capable of learning and provides appropriate opportunities to do so, then many skills can be developed, or improved. In addition, the impact of management practices can be reduced by including choices such as *when, where, how,* or *who with*, even when bureaucracy or duty of care prevents the choice of *what* or *whether*. For instance, choices may be made regarding morning or evening, shower or bath, or whom to assist, even when the choice of whether or not wash is not considered permissible.

Improving Opportunities for Choice

In response to the question about what could be done to improve the opportunities for residents to make choices in daily-living areas (Table 6.4), support workers were able to come up with a range of valuable suggestions. That support workers are aware of measures that can be taken but do not always implement them may indicate that lack of motivation is one of the first barriers that needs to be overcome to improve choice opportunities.

The most obvious ways to improve choice opportunities are to offer more choices and make use of communication aids to make the presentation of options clear. Respondents also recognised that they needed training to learn how to do this for individual residents, and to become more aware of their own influence. In addition, residents need to be encouraged and taught how to respond in order to overcome any limitations in past experience. Some of the suggestions such as increasing resources and reducing the number of staff in a house, although valid, are outside the scope of this study.

Improving Ability to Make Choices

Support workers also recognised that the best way to improve the abilities of residents with intellectual disabilities to make choices (Table 6.5), is to provide opportunities to practise making choices, and encourage them to respond. The use of communication aids is important not only for the presentation of options but also to provide means for the resident to communicate preferences.

Another suggestion was to assess the level of disability of the residents and determine their potential for developing choice-making skills. This issue is explored in later studies but is complicated by how to measure the level of disability and the relationship between this assessment, the functional disability, and the capacity to learn. It may be more useful to determine a baseline level of choice-making for each individual (Study Three) and aim to improve on that up to the level of the general community (Study Six). This, however, introduces the question of whether the same training approach will benefit individuals with different degrees of disability.

Another issue that is raised by this point, is what part the support workers' perceptions of the level of disability plays in determining how they promote the development of the resident's choice-making skills. This issue will be considered further in Study Five.

CONCLUSION

When support workers were asked to provide answers to what could be done to improve choice-making in the two areas of interest in this study i.e. provision of opportunities and development of skills, they were able to come up with many valuable suggestions. Despite the knowledge of what could be done, provision and promotion of choice, even in the most important daily-living areas, still appeared to be limited. There are a number of possible explanations for this, one is that the motivation or incentive to do things differently may be lacking; another is that training choice is given relatively low priority in the range of tasks expected of support workers; and a third is that support workers lack the knowledge of required to implement their ideas.

Any training in making choices should therefore address issues of motivation and knowledge of how to initiate change for individual residents, in order that the support worker be given both the incentive and the means to make choice a high priority.

Chapter Seven

STUDY TWO – QUESTIONNAIRE DEVELOPMENT

INTRODUCTION

This study builds on the information gathered in the previous study in order to answer the first of the key questions of this thesis: how can choice be measured?

Once the components of choice-making have been analysed, and the focus areas of choice have been identified, the next step is to develop a suitable instrument to measure the baseline development of the choice behaviour aspects of interest and evaluate training in choice-making skills. As an existing instrument was not located, a comprehensive Daily Choice Questionnaire needed to be developed.

Type of Instrument

The first stage in the development of an assessment instrument was to decide on the style of instrument. There are three basic methods of assessing behaviour, these are: observation, self-report, and third-party report.

Observation

Observations are one of the most basic ways of recording behaviour but they are very time consuming and do not provide information on attitudes. As the intention was to record repeated episodes of choice behaviours in several different choice areas, in natural settings throughout the day; the use of direct observation was not a viable option. Even the use of videotape recording was not practical due to the likelihood that the choice behaviour would occur in different parts of the residence, at any time of day. Therefore, this method of recording behaviour was rejected for the purposes of this thesis.

Self Report

Another common method of recording behaviour is to rely on the self-report of the individual being assessed. Although this can be done in either a verbal or written form, it is a difficult task for people with intellectual disabilities as most professionals have little experience with questioning this population and fail to adapt their vocabulary and interviewing techniques (Wadsworth & Harper, 1991). This can lead to the opinions and information provided by people with intellectual disabilities being discounted as unreliable and invalid. Skilful questioning can elicit reliable and clinically useful data about moods, thoughts, preferences, and living environments if questions are structured and supported. Picture cues can increase the temporal reliability of self-report. Self-report can be a valuable means of collecting information as the resident is likely to be the best judge of his or her own living situation and quality of life.

Self-report by people with an intellectual disability however, does have a lot of problems and sometimes proves to be unusable. Residents either cannot answer questions or cannot provide accurate answers to the questions they do answer. Residents have a tendency to try to please the interviewer by trying to give the right or expected answer; it is therefore necessary to diffuse any fear of giving a negative opinion by emphasising that there are no right or wrong answers and they are not being evaluated or judged. It is essential to develop a sense of trust and privacy and ask questions slowly without pressure to respond quickly.

Questions should be phrased clearly and with a minimum of words. Open-ended questions can be useful as it is important to encourage responses in the resident's own words, and not to supply suggestive answers. It is also best to avoid questions that require futuristic or speculative thinking. Questioning may be aided through the use of pictures, photos, or real objects.

Although some studies have found agreement between resident and third-party reports, there is also considerable evidence that residents believe that they make more decisions than perceived by support workers. This may be due to response acquiescence, residents making choices to

please support workers, or residents may equate satisfaction with the outcome as choice (Jenkinson, Copeland, Drivas, Scoon & Yap, 1992).

As with observation techniques, the time-consuming nature of self-report, the complexity of the questions to be asked, and the possible response biases, made this approach unviable for this study. It was, however, recognised that residents had the right to choose whether or not to participate in the research, so many of the techniques described above were used to obtain informed consent regarding participation directly from the residents whenever possible.

Support Worker Report

The third approach is to rely on the opinions of support workers. Traditionally the subjective opinions of caregivers have been used to identify resident preference. However some studies have shown that asking support workers about preferences, generally gives no indication at all of what the resident would say if asked the same question. Support worker opinions of resident's food preferences were assessed using a five point rating scale by Parsons and Reid (1990). They found that support worker opinions of participant preferences did not coincide consistently with the results of the systematic assessment. This is possibly because although support workers knew the resident's strongest preferences, they could not identify preferences between two specific items.

Differences in self-report and support workers' ratings of choice involvement have been identified in a number of studies (Jenkinson, Copeland, Drivas, Scoon & Yap, 1992) and can be interpreted in a number of ways. Rapley, Ridgway and Beyer (1997) proposed that support workers' responses were less valid as they were biased towards desirable outcomes. However, Stancliffe and Parmenter (1999) suggested that both support worker and resident measures are valid but represent differing viewpoints. One of the reasons for difference may be that judgement is relative and a rating will depend, in part, on whom one compares oneself with (Stancliffe, 1995).

There may also be differences between the ratings of different support workers. These may be due to: different biases; different frames

of reference; different sets of behaviour being observed; or because the presence of different support workers influences the expression of choice in different ways, perhaps through increased opportunities or encouragement. However, Kearney, Durand, and Mindell (1995) suggested that the development of assessment measures targeting the viewpoints of direct-care staff should be explored further.

For practical reasons, the use of support worker report was determined to be the most appropriate form of assessment for this thesis, as repeated measurements were required over the course of a whole day and a focus on a range of choice aspects rather than a simple indication of choice availability. Furthermore, the questions to be examined are not based on opinions of resident preference but on more specific aspects of choice. It is important, however, to determine how consistent these responses are across time and between support workers, and to keep in mind the source of the responses when making interpretations.

Choice Areas

The daily choice-making areas used in the questionnaire (food, clothing, leisure and hygiene), are the areas identified in the previous chapter as the most important areas of daily living for adults with an intellectual disability to make choices in. Longer lists of potential questions in each area were reduced through consultation with support workers and members of the general community. The final four specific choice questions in each area consisted of choices that could reasonably be expected to occur every day for most people. The choices were then divided into those most likely to occur in the morning or the afternoon, so that a support worker could complete one version of the questionnaire during the course of a normal shift. The final list of choices overlapped with six of the ten choices in the Life Choices Survey used by Kishi, Teelucksingh, Zollers, Park-Lee & Meyer (1988), and 10 of the 25 choices in the Resident Choice Assessment Scale (RCAS) developed by Kearney, Durand, and Mindell (1995).

Aspects of Choice Behaviour

The next step was to clarify the aspects of choice behaviour to be measured. Although no suitable choice instruments were identified prior to the collection of data, several instruments have been published since. The Choice Questionnaire (Stancliffe & Parmenter, 1999) is a 26-item scale which uses a three-point Likert scale to measure the degree of choice exercised in a number of areas. The focus on a single global measure of choice rather than examining each aspect of choice behaviour individually, would have made the Choice Questionnaire unsuitable for the purposes of evaluating training on the different stages of choice. Furthermore, the items did not occur on a daily basis and included choices that were outside the residential context.

The Resident Choice Assessment Scale (Kearney, Durand & Mindell, 1995) mentioned earlier, consisted of 25 items and proved to be reliable across time and across raters. Direct care staff acted as raters, and indicated the availability of choice for each item, from never to always, on a 7 point Likert-type scale. Although the Resident Choice Assessment Scale (RCAS) had not been published at the time of the development of the Daily Choice Questionnaire, it would not have been considered appropriate for the intended research as it also includes choices outside the group home, as well as some choices that would not be expected to change following a short-term training programme. In addition, the focus on *choice availability* alone, made it too narrow for the purpose of evaluating the training programme.

Design of the questionnaire required the selection of questions that would describe the aspects of choice behaviour in terms of both resident and support worker behaviour. Except for the first question, all aspects of choice behaviour were designed to relate to a specific choice during the course of the support worker's current shift. The first question gave an indication of general experience in making the specific choice. The other aspects of choice behaviour to be examined fell into the three basic stages of choice: *Option Recognition*, *Evaluation And Selection*, and *Acting On The Selection*, and utilised some of the classification categories outlined by Shaddock, Zilber, Guggenheimer, Dowse, Bennett and Browne

(1993), and the coding categories used by Rawlings, Dowse and Shaddock (1995).

Stage A: Option Recognition

The resident aspect of choice behaviour in the *Option Recognition* section of the questionnaire regarded whether the resident initiated an opportunity for the specific choice. This was part of a broader question assessing whether there was an opportunity for the choice at all, and whether the resident or another initiated it.

The remaining aspects of choice behaviour examined in this section related only to choices initiated by another and thus described support worker aspects of choice behaviour. Responses to these questions indicated the form of communication use to present choice opportunities, whether the options were in view, and how many options were specified.

Stage B: Evaluation and Selection

The *Evaluation and Selection* part of the questionnaire focussed on the influences on the choice, and the responses to the opportunity. The first question in this section consisted of a list of possible limitations relating to either the resident or the environment. A question on influences on choice described support worker aspects of choice behaviour. Influence types included the provision of information about options or consequences, and whether encouragement or discouragement was provided. Resident aspects of choice behaviour were examined through questions assessing the emotional response, and whether the resident communicated a response to the choice opportunity.

Stage C: Acting on the Selection

Once an option has been selected and communicated, the third stage of the questionnaire, *Acting on the Selection*, assesses the support worker reactions to the resident's response. This was followed by a question that determined the contribution of the resident and the support worker to following through with the choice, and whether it was followed through immediately or after a delay.

The final two aspects of choice behaviour examined by the questionnaire looked at a number of specific ways that the choice may have impacted on the resident or others.

Reliability

Once constructed, the questionnaire needed to be assessed for test-retest reliability, and inter-rater reliability in order to refine the questions for further analyses in future studies. Test-retest reliability gives an indication of how consistently the questionnaire is completed for a given resident during a limited period of time. It involves comparing two randomly selected responses about a resident by the same support worker. Inter-rater reliability gives an indication of whether different support workers complete the questionnaire in a similar manner. This form of reliability compares two randomly selected responses about a resident by two different support workers.

High test-retest reliability suggests that the question is reasonably robust and is thus a reliable source of information. Low test-retest reliability would therefore be grounds for excluding a choice aspect or option from future analyses or an indication that options may need to be merged into more general categories in order to increase the dependability of the information obtained. Inter-rater reliability however, does not necessarily indicate that the information is unreliable, but may simply indicate that support workers influence or perceive the choice in different ways. Low reliability in this area is therefore not necessarily grounds for exclusion or merging of options but flags the possibility or support worker differences.

METHOD

Dependent Variables

The dependent variables in these analyses were the baseline responses to the Daily Choice Questionnaire for all residents recruited for the purpose of the training to be reported in Study Four. The Daily Choice Questionnaire consisted of fourteen questions that were completed for

sixteen specific daily choices. The questionnaire was presented as a question sheet with the questions in full (Appendix 2.1), and an answer sheet for responses which contained only question numbers and key words (Appendix 2.2). Each question required ticking the box on the answer sheet next to the appropriate alternative or alternatives from a list of possible responses. The questions are summarised in Table 7.1.

Table 7.1: Summary of choice aspect questions from the Daily Choice Questionnaire.

	QUESTION		OPTIONS
1	Has the person had any experience in making choices in the above area?		**NO**
		(a)	**Occasionally**
		(b)	**Frequently**
	OPTION RECOGNITION		
2	Did the person have an opportunity to make a choice in this area during the current shift? If YES, what form did the opportunity take?		**NO**
		(a)	Opportunity occurs regularly as part of the persons **routine** (not presented explicitly)
		(b)	Options available within immediate **environment** (not presented explicitly)
		(c)	Presented **explicitly** by another
3	Which form(s) of communication were used to present the choice opportunity?	(a)	**Real objects**
		(b)	**Photographs**
		(c)	**Pictures**
		(d)	**Gestures**
		(e)	**Speech**
		(f)	**Signing**
		(g)	**Compic** (symbols)
		(h)	**Written words**
4	When the choice was offered were the options in view	(a)	**YES**
		(a)	**NO**
5	Were the options specified? If YES, how many options were there?		NO (i.e. **open** choice)
		(a)	**One option**
		(b)	**Two options**
		(c)	**Three options**
		(d)	More than three (**many**)
	EVALUATION AND SELECTION		
6	Were there any limitations on the person's choice? If YES, which limitations affected the person's choice?		**NO**
		(a)	**Ability**
		(b)	**Experience**
		(c)	**Communication**
		(d)	**Health**
		(e)	**Time**
		(f)	**Finances**
		(g)	**Resources**
		(h)	Social constraints (**society**)
		(I)	**Inclination**
		(j)	**Programme**

cont.

QUESTION	OPTIONS
7 Did others (i.e. support workers or other people) attempt to influence the person's choice? If YES, how did they attempt to influence them?	**NO** (ai) Information on **options** (aii) Information on **consequences** (bi) Encouraging and **facilitating** a response (bii) **Discouraging** a response
8 Did the person show any emotional response to the choice opportunity? If YES, what form did the emotional response take?	**NO** (a) **Calm** and confident in the choice situation (b) **Confused** and uncertain how to respond (c) **Distressed** and unable to respond
9 Did the person communicate a response to the choice opportunity? If YES, what form of communication was used?	**NO** (a) **Action** (b) **Vocalisation** (c) **Gesture** (d) Communication **aid**
ACTING ON THE SELECTION	
10 Did others react to the person's response? If YES, what form did the reaction take?	**NO** (a) Acknowledged or unquestioningly **accepted** (b) Meaning of response **clarified** in neutral manner (c) Convinced to change response **(challenged)** (d) Response **disregarded** or not complied with
11 Was the choice followed through with?	**NO** (a) **Resident** (b) **Support worker** (c) **Other**
12 When was the choice followed-up?	(a) **Immediately** (b) **After a delay**
13 Did the choice opportunity or response have an impact on the person making the choice?	(a) **NO** (b) Required a change in the resident's **routine** (c) Resulted in a new **experience** (d) Increased the person's **independence** (e) Generally **negative** impact
14 Did the choice opportunity or response have an impact on others?	(a) **NO** (b) **Interfered** with the choices of others (c) Required **extra work** from support worker (d) Resulted in **less work** for support workers (e) Generally **negative** impact

Sixteen daily choices were examined, four from each of the areas of food, clothing, hygiene and leisure (see Table 7.2). The specific choices selected were those available on a daily basis in the context of a group home environment. The items included choices regarding when, and where, as well as what, residents could choose. The list of specific choices was compiled through consultation with support workers and other professionals with experience in working with people with a disability, and members of the general community.

There were two forms of the questionnaire, one examining choices that occurred in the morning, and one focussing on choices in the afternoon and evening. Half of each of the food and clothing choices appeared on the morning version of the questionnaire, and half on the evening version. However, all hygiene choices were on the morning questionnaire, and all leisure choices were on the evening questionnaire, due to the nature of the choices and the most likely timing of their occurrence.

Table 7.2: Daily choices from each of the four choice areas from the Daily Choice Questionnaire.

CHOICE AREA	MORNING CHOICES	AFTERNOON CHOICES
Food	What to eat for breakfast?	Help self to a snack?
	Where to eat breakfast?	Serve own tea
Clothing	Which clothes to put on?	When to wash clothes?
	When to get dressed?	When to change for bed?
Leisure		Whether to go out?
		Spend time alone?
		What to watch on TV?
		When to go to bed?
Hygiene	When to have a wash?	
	Bath or shower?	
	Wash hair or not?	
	Whether to clean teeth?	

Procedure

The consent procedure for all participants began with obtaining permission from the residential support services and their relevant boards of management to approach individual houses. House managers and support workers were then informed about the training programme and its participation requirements before consent was sought from at least four regular support workers in each house.

Only then were residents and/or a defacto guardian approached in order to gain consent for the participation of residents themselves. A defacto guardian was someone who knew the individual well but was not directly involved in the study, i.e. a family member who had regular contact, or staff member not involved as a support worker participant. A person familiar with the resident's communication was used to help explain the requirements of involvement to the resident with the aid of

computer-generated pictographs (compic) where appropriate. If possible, consent was given by the resident, if not, the defacto guardian was asked to consent on his or her behalf, once they were confident that participation would not be detrimental to the resident. The participation of a household only went ahead if all residents agreed to be involved but it was made clear that they need only be involved in the sessions they wished to. All data collected in relation to the study was coded to maintain confidentiality.

In order to record a thorough baseline, a number of support workers from each house were requested to complete the questionnaire on eight occasions for each resident, four on weekdays and four on weekends, half of which were morning, and half evening questionnaires, during a period of approximately two weeks. Completion of the questionnaires was shared between the support workers to be involved in the subsequent training study. Selection of the support worker to complete a specific questionnaire was scheduled using staff rosters and limited by the need to distribute the questionnaires between mornings and afternoons, and weekdays and weekends.

Respondents

Households

Initially the residents and support workers from twelve fully staffed shared houses, were recruited to participate in assessing the effectiveness of the choice-making training package. The houses were run by seven different residential support services. Unfortunately, due to problems within one of the services, one of the houses dropped out leaving eleven households to participate in the training. Studies Two and Three examine the information compiled from the baseline of this training study, while Study Four will examine the training itself.

Resident Participants

A total of 43 resident participants were involved at baseline, the details of the characteristics of these residents are presented in detail in the following study. In summary, 63% of residents were female and 37%

male, and they ranged in age from 20 to 76 years. The level of intellectual disability was rated by house managers as mild for 28% of participants, moderate for 54%, and 18% were rated as severe. Fifteen (36%) of residents were also indicated to have some form of physical disability.

Eighty-four percent of participants had spent time in an institution. The period of institutionalisation ranged from 18 months to 70 years, with an average of 23 years. The mean time since leaving the institution was 28 months but varied from 12 months to four and a half years. Residents had lived in their current houses for between five months and four years, with an average residence of 23 months.

Support Worker Participants

Although a total of 58 support workers were involved in the training (Study Four), at baseline there were only 43. There were between two and six support worker raters per household. It is these 43 raters that will be examined in Studies Two and Three.

Details of the support worker characteristics are described in detail in Study Three, however in summary 70% were female and 30% male, and they ranged in age from 19 to 54 years of age, with an average of 35 years. They had generally worked in the disability field for an average of 4 years (ranging from 2 months to 25 years), with an average 15 months in the present household (one month to 5 years). Forty percent were employed on a full time basis, 32% part time, and 28% on a casual basis, with the result that they spent an average of 29 hours (between 15 and 40 hours) per week in the house. Of the 22 support workers who responded to the qualifications question, six had no formal qualifications, fourteen had completed or were currently completing a Technical and Further Education (TAFE) qualification in the disability field, and two had formal qualifications in other fields.

Analyses

Test-Retest Reliability

The test-retest reliability of each option for each choice aspect of choice behaviour question was examined individually. Whenever

available, two baseline responses to a given option, for each resident by the same support worker, were randomly selected for each of the 16 daily choices examined. For both of the sets of data created, the average responses for the food, clothing, leisure and hygiene daily choices, were then calculated, as well as an overall choice score. As it was the difference between food and all other choice areas that was to be of interest in Study Four, the clothing, leisure and hygiene scores were averaged leaving three scores: one for choices overall, for food choices only, and for 'other' daily choices.

The two sets of responses for each score were then compared using a two-tailed Pearson correlation. Reliability was considered to be sufficient if the correlation coefficient was at least 0.5 and reached a significance level of 0.01. A correlation coefficient of 0.5 was considered by Cohen (1992) to indicate a large correlation. The process was then repeated for each option for each choice stage question.

In this section, approximately 177 correlations were completed to assess test-retest reliability. Of these, 129 proved to be sufficiently correlated (an additional 7 correlations were significant at the 0.01 level, although *R* was less than 0.5, and 10 correlations could not be completed due to empty cells). On the basis of a Type I error rate of 0.01, only two of the significant results would be expected to be due to chance, leaving a further 127, or approximately 98% of the significant findings, reflecting genuine psychological effects.

Inter-Rater Reliability

The procedure used to construct sets of data for test-retest reliability was repeated for inter-rater reliability with the exception that the responses of two different support workers were randomly selected for each resident. These sets were compared using two-tailed Pearson correlations, and reliability was again considered sufficient when the correlation coefficient was at least 0.5 with a significance level of 0.01.

Approximately 177 correlations were completed to assess test-retest reliability. Of these, 104 proved to be sufficiently correlated (an additional 18 correlations were significant at the 0.01 level, although *r* was

less than 0.5, and 3 correlations could not be completed due to empty cells). On the basis of a Type I error rate of 0.01, only two of the significant results would be expected to be due to chance, leaving a further 102, or approximately 98% of the significant findings, reflecting genuine psychological effects.

RESULTS

(1) Choice Experience

The first question on the Daily Choice Questionnaire was whether the person had any experience making choices in the specific choice area. Overall responses were either *'no'* (23%), *'occasionally'* (11%), or *'frequently'* (66%).

Both the test-retest and inter-rater reliability assessments of the random sets show that there was generally a high degree of reliability for each response for choices overall, and for both food and other daily choice areas, except for the inter-rater reliability of responses to occasional experience (Table 7.3). For this reason, responses were reduced to simply experience – *'yes'* (77%) or *'no'*.

Table 7.3: Results of test-retest (T-R) and inter-rater (I-R) reliability assessments for question one on choice experience, of the Daily Choice Questionnaire.

EXPERIENCE CHOICE ASPECTS		CHOICE AREA					
		OVERALL		FOOD		OTHER	
		N	*r*	*N*	*r*	*N*	*r*
No/Yes	T-R	38	0.94***	38	0.65***	38	0.93***
	I-R	42	0.88***	42	0.61***	42	0.85***
Occasionally	T-R	38	0.77***	38	0.44**	38	0.75***
	I-R	42	0.62***	42	0.49**	42	0.49***
Frequent	T-R	38	0.92***	38	0.51**	38	0.90***
	I-R	42	0.87***	42	0.58***	42	0.87***

Note: Highlighted results met the conditions for adequate reliability.
*$p<0.05$ **$p<0.01$ ***$p<0.001$

Stage A: OPTION RECOGNITION

(2) Opportunities for Choice

The next question asked whether the person had an opportunity to make a choice in the specific choice area during the current shift. Overall responses consisted of *'no'* (33%), *'explicit'* (20%), *'routine'* (41%), or

'environment' (6%). The last three options described the type of opportunity. Explicit opportunities were initiated and presented by another, while routine and environmental opportunities were both initiated by the resident and differed only in the degree of regularity that they were accessed.

Table 7.4: Results of test-retest (T-R) and inter-rater (I-R) reliability assessments for question two on choice opportunity, of the Daily Choice Questionnaire.

OPPORTUNITY CHOICE ASPECTS		CHOICE AREA					
		OVERALL		FOOD		OTHER	
		N	*r*	*N*	*r*	*N*	*r*
No/Yes	T-R	38	0.95***	38	0.74***	38	0.93***
	I-R	42	0.90***	42	0.59***	42	0.84***
Explicit (Other-initiated)	T-R	38	0.34*	38	0.24	38	0.40*
	I-R	42	0.67***	42	0.40**	42	0.57***
Routine	T-R	38	0.91***	38	0.62***	38	0.89***
	I-R	42	0.86***	42	0.64***	42	0.81***
Environment	T-R	38	0.68***	38	0.38*	38	0.56***
	I-R	42	0.33*	42	0.27	42	0.22
Resident-initiated	T-R	38	0.90***	38	0.64***	38	0.87***
	I-R	42	0.85***	42	0.52***	42	0.77***

Note: Highlighted results met the conditions for adequate reliability.
*$p<0.05$ **$p<0.01$ ***$p<0.001$

Test-retest and inter-rater reliability assessments of the randomly selected response sets presented in Table 7.4 show that although there was a high degree of reliability (0.95 and 0.90 respectively) regarding whether or not an opportunity had been presented, there was less reliability regarding what form that opportunity took. For this reason two of the opportunity categories were merged to leave the *'other-initiated'* – initiated explicitly by another, and *'resident-initiated'* categories (47%) - initiated by the resident themselves through routine or environment.

(3, 4, 5) Choice Presentation (Other-initiated)

Question Three of the Daily Choice Questionnaire examined the form(s) of communication used to present opportunities explicitly: *'speech'* (68%), *'real objects'* (29%), *'gestures'* (13%) and *'signing'* (4%). Photographs, pictures, compic and written words were not used at baseline and were thus eliminated from further analyses, similarly the response rate to signing was too low to analyse further. Question Four indicated whether the options were *'in view'* when the opportunity was

offered (70%), and Question Five looked at how many options were specified: an *'open'* choice had no options (37%), or a closed choice with *'one'* (21%), *'two'* (23%), *'three'* (6%), or *'many'* options (12%). This is in contrast to the frequency of provision of a single option for 89% of choices in day placement settings found by Shaddock, Zilber, Guggenheimer, Dowse, Bennett and Browne, (1993).

Table 7.5: Results of test-retest (T-R) and inter-rater (I-R) reliability assessments for questions three, four and five on choice presentation, of the Daily Choice Questionnaire.

PRESENTATION CHOICE ASPECTS		CHOICE AREA					
		OVERALL		FOOD		OTHER	
		N	*r*	*N*	*r*	*N*	*r*
COMMUNICATION							
Speech	T-R	26	0.88***	13	**0.62***	22	0.60**
	I-R	31	0.62***	21	0.20	25	0.20
Real objects	T-R	28	0.72***	16	0.79***	20	0.96***
	I-R	35	0.75***	20	0.71***	31	0.66***
Gestures	T-R	27	0.76***	12	0.95***	21	0.80***
	I-R	30	0.02	23	-0.07	26	0.62**
OPTIONS							
In view	T-R	23	0.79***	14	-0.16	16	0.86***
	I-R	28	0.01	20	0.33	23	0.26
Open/Closed	T-R	24	0.57**	13	**0.67***	16	0.72**
	I-R	30	0.16	20	0.41	26	0.11
Number	T-R	24	0.81***	13	0.76**	16	0.80***
	I-R	30	**0.43***	20	0.10	26	0.14

Note: Highlighted results met the conditions for adequate reliability.
*$p<0.05$ **$p<0.01$ ***$p<0.001$

Test-retest and inter-rater reliability assessments of the random sets presented in Table 7.5 show that the reliability of the communication form used to present choices, was generally quite high. However, whether options were in view, and how many options were offered had high test-retest reliability for choices overall but not for food choices, and had very low inter-rater reliability in all cases. This suggests that there were differences between how support workers presented choice opportunities. This may indicate problems with the questions, or be due to the relatively low rate of response to these questions. As a result Questions Four and Five were eliminated from further analyses.

Stage B: EVALUATION AND SELECTION

(6) Limitations on Choice

Question Six explored the limitations (33%) on choice. The forms of limitations were: *'ability'* (17%), *'time'* (10%), *'communication skills'* (7%), *'experience of options'* (6%), *'health factors'* (5%), *'resources'* (3%), *'social constraints'* (2%), *'finances'* (<1%), *'inclination'* (<1%), and *'programme involvement'* (0%). Reliability was not assessed for the latter four limitation types as response rates were too low.

Table 7.6: Results of test-retest (T-R) and inter-rater (I-R) reliability assessments for question six on limitation types, of the Daily Choice Questionnaire.

LIMITATION CHOICE ASPECTS		CHOICE AREA					
		OVERALL		FOOD		OTHER	
		N	*r*	*N*	*r*	*N*	*r*
No/Yes	T-R	38	0.90***	34	0.57***	37	0.85***
	I-R	41	0.75***	39	0.49**	41	0.71***
RESIDENT							
Ability	T-R	37	0.82***	34	0.63***	36	0.90***
	I-R	42	0.79***	40	0.49**	42	0.56***
Communication	T-R	38	0.94***	34	0.95***	37	0.93***
	I-R	41	0.54***	38	0.65***	41	0.62***
Experience	T-R	37	0.46**	34	0.65***	37	0.75***
	I-R	42	0.89***	38	0.32	42	0.89***
Health	T-R	38	-0.05	34	0.51**	37	-0.02
	I-R	41	0.56***	38	0.36*	40	0.66***
ENVIRONMENT							
Time	T-R	38	0.77***	33	0.01	37	0.76***
	I-R	42	0.56***	40	0.08	42	0.35*
Resources	T-R	37	-0.05	34	-0.04	37	
	I-R	42	0.16	40	0.31	42	-0.05
Resident	T-R	38	0.83***	34	0.64***	36	0.85***
	I-R	42	0.83***	39	0.51**	42	0.77***
Environment	T-R	37	0.78***	34	0.47**	36	0.87***
	I-R	42	0.61***	40	0.09	42	0.53***

Note: Highlighted results met the conditions for adequate reliability.
*$p<0.05$ **$p<0.01$ ***$p<0.001$

Test-retest and inter-rater reliability assessments of the randomly selected sets presented in Table 7.6 show that the reliability of presence of limitations on choice was quite high overall (0.90 and 0.75 respectively). Although the reliability of the most frequently reported limitations was also quite high, the reliability for many types of limitations was very low, or was not testable due to empty cells. For this reason, limitation types were grouped into two categories: those that referred to limitations of the

'resident' (24%) and those that referred to the *'environment'* (15%). Both of these categories were deemed to have adequate reliability, at least for choices overall, and the 'other' daily choice area category.

(7) Influences on Choice

Question Seven of the Daily Choice Questionnaire examined possible influences on resident choice (20%). The types of influence focussed on were provision of *'information'* (12%) - either on *'options'* (10%) or *'consequences'* (2%), and *'motivation'* of a response (11%) - either *'facilitating'* (10%) or *'discouraging'* (<1%).

Table 7.7: Results of test-retest (T-R) and inter-rater (I-R) reliability assessments for question seven on influences on choice, of the Daily Choice Questionnaire.

INFLUENCE CHOICE ASPECTS		CHOICE AREA					
		OVERALL		FOOD		OTHER	
		N	*r*	*N*	*r*	*N*	*r*
No/Yes	T-R	38	0.74***	33	0.64***	35	0.52**
	I-R	42	0.79***	36	0.71***	41	0.75***
Information	T-R	38	0.62***	32	0.53**	35	0.19
	I-R	42	0.56***	35	0.35*	41	0.41**
Options	T-R	38	0.68***	33	0.59***	35	0.34*
	I-R	42	0.65***	39	0.27	42	0.49**
Motivation	T-R	38	0.66***	30	0.77***	34	0.82***
	I-R	41	0.74***	36	0.74***	41	0.71***
Facilitate	T-R	37	0.74***	33	0.59***	32	
	I-R	42	0.61***	38	0.57***	42	

Note: Highlighted results met the conditions for adequate reliability.
*$p<0.05$ **$p<0.01$ ***$p<0.001$

Table 7.7 shows that the test-retest reliability and inter-rater reliability assessments of random sets of responses on the presence of influences on choice was quite high (0.74 and 0.79 respectively), as were the basic categories of influence – information and motivation. However, as the response rates to the information on *consequences* and *discouragement* of choice categories were too low to assess reliability, these questions were not used in later analyses.

(8) Emotional Responses to Choice

Question Eight considers the emotional responses of the residents to choice opportunities. Response categories were: *'none'* (45%), *'calm'* and confident in choice situation (51%), *'confused'* and uncertain how to respond (3%), and *'distressed'* and unable to respond (1%).

Table 7.8: Results of test-retest (T-R) and inter-rater (I-R) reliability assessments for question eight on emotional responses, of the Daily Choice Questionnaire.

EMOTION CHOICE ASPECTS		CHOICE AREA					
		OVERALL		FOOD		OTHER	
		N	*r*	*N*	*r*	*N*	*r*
No/Yes	T-R	37	0.86***	33	0.70***	37	0.76***
	I-R	41	0.81***	40	0.46**	40	0.48**
Calm	T-R	37	0.82***	33	0.60***	37	0.77***
	I-R	42	0.69***	38	0.43**	41	0.53***
Confused	T-R	38	-0.04	33	-0.03	36	
	I-R	42	0.81***	36	0.91***	42	0.65***
Distressed	T-R	37	0.32	33		37	0.55***
	I-R	42	0.47**	38		41	0.47**
Neutral	T-R	38	0.22	34	-0.03	37	0.31
	I-R	42	0.70***	38	1.00***	41	0.48**

Note: Highlighted results met the conditions for adequate reliability.
*$p<0.05$ **$p<0.01$ ***$p<0.001$

The test-retest and inter-rater reliability assessments of random sets of these responses presented in Table 7.8 indicate that the reliability of the presence of an emotional response was very good (0.86, 0.81). However, there appeared to be no logical difference between *'no'* emotional response and *'calm'* responses so these two categories were merged to form a *'neutral'* category with adequate inter-rater reliability. However, this resulted in 96% of responses being *'neutral'*, and combined with the very low response rates for the other two options, this question was eliminated from further analyses.

(9) Responses to Choice

Question Nine assesses whether the resident responded to the choice opportunity (77%) and how they communicated the response. The response categories included: *'action'* (56%), *'vocalisation'* (24%), *'gesture'* (7%), and *'aid'* (1%). The response rate for the last option was too low to analyse further.

The test-retest and inter-rater reliability assessments of randomly sets of responses presented in Table 7.9 show that the reliability of a response being indicated was quite high (0.86, 0.63) for choices overall, as was the reliability of the three more frequent response types.

Table 7.9: Results of test-retest (T-R) and inter-rater (I-R) reliability assessments for question nine on choice response types, of the Daily Choice Questionnaire.

RESPONSE CHOICE ASPECTS		CHOICE AREA					
		OVERALL		FOOD		OTHER	
		N	*r*	*N*	*r*	*N*	*r*
No/Yes	T-R	37	0.86***	34	0.52**	37	0.85***
	I-R	42	0.63***	39	0.24	42	0.31*
Action	T-R	37	0.83***	34	0.62***	37	0.80***
	I-R	42	0.50**	39	0.11	42	0.48**
Vocalisation	T-R	37	0.80***	34	0.68***	37	0.87***
	I-R	42	0.80***	37	0.79***	42	0.77***
Gesture	T-R	38	0.68***	33	0.47**	37	0.47**
	I-R	41	0.88***	37	0.95***	41	0.75***

Note: Highlighted results met the conditions for adequate reliability.
*$p<0.05$ **$p<0.01$ ***$p<0.001$

Stage C: ACTING ON THE SELECTION

(10) Reactions to Choice Responses

Question Ten focuses on the reactions of others, particularly support workers, to the resident's response to the choice opportunity. Overall categories were: '*none*' (64%), '*accepted*' (31%), '*clarified*' (3%), '*challenged*' (1%), and 'disregarded' (<1%). These last two categories could not be assessed for reliability due to low response rates.

Table 7.10: Results of test-retest (T-R) and inter-rater (I-R) reliability assessments for question ten on others reactions to choice responses, of the Daily Choice Questionnaire.

REACTION CHOICE ASPECTS		CHOICE AREA					
		OVERALL		FOOD		OTHER	
		N	*r*	*N*	*r*	*N*	*r*
No/Yes	T-R	38	0.78***	33	0.46**	36	0.57***
	I-R	42	0.74***	35	0.35*	42	0.60***
Accept	T-R	38	0.78***	34	0.40*	36	0.64***
	I-R	41	0.73***	38	0.39*	41	0.63***
Clarify	T-R	38	0.97***	32	0.57**	37	0.71***
	I-R	41	0.54***	40	-0.08	41	0.61***
No/Accept	T-R	38	0.50**	33	0.75***	36	0.48**
	I-R	42	0.37*	35	-0.11	42	0.54***
Reject	T-R	37	-0.05	33		37	-0.04
	I-R	41	0.09	39	-0.04	41	0.06

Note: Highlighted results met the conditions for adequate reliability.
*$p<0.05$ **$p<0.01$ ***$p<0.001$

The test-retest and inter-rater reliability assessments of random sets of responses to this question are presented in Table 7.10. These indicate that the answer to the presence of a reaction to the resident

response was highly reliable (0.78, 0.74) for choices overall, but not for food choices. Similar results were found for the reliability of the two more frequent reaction types.

As with emotional responses however, there was no logical reason for the distinction between no reaction and *'acknowledged or unquestioningly accepted'* reaction, so these two categories were merged to form an *'accepting'* category (95%). In addition, as the response rates to the last two reaction types were very low, these were merged to form a *'rejecting'* category (2%), however, response rates were still too low to effectively assess reliability. As with the emotional response question, the imbalance in responses to this question led to its elimination from further analyses.

(11, 12) Follow-Through of Choice

Question Eleven of the Daily Choice Questionnaire indicates whether the choice was followed through (96%), and by whom: *'resident'* (95%), *'support worker'* (79%), or *'other'* (4%). Although not all those who indicated that the choice had been followed through completed the next question, Question Twelve indicated whether the choice was followed up *'immediately'* (72%) or *'after a delay'* (6%).

Table 7.11 shows that although the test-retest reliability of random sets of responses was sufficient for the frequency of follow-through, the inter-rater reliability was poor. Both forms of reliability were good for the responses to resident follow-through, however even when the *'support worker'* and *'other'* categories were merged, due to lack of response to the *'other'* category, reliability remained low.

New categories were created to emphasise independence, which indicated whether the resident participated in follow-through alone or with assistance. The categories: *'resident alone'* (63%), *'resident and other'* together (17%), and *'other alone'* (16%), all had sufficient reliability, at least for choices overall.

Table 7.11: Results of test-retest (T-R) and inter-rater (I-R) reliability assessments for questions eleven and twelve on follow-through of choice, of the Daily Choice Questionnaire.

FOLLOW-UP CHOICE ASPECTS		CHOICE AREA					
		OVERALL		FOOD		OTHER	
		N	*r*	*N*	*r*	*N*	*r*
No/Yes	T-R	37	0.55***	34	-0.04	37	0.80***
	I-R	42	0.36*	37	0.13	42	0.27
Resident	T-R	35	0.61***	29	0.50**	32	0.61***
	I-R	38	0.62***	34	-0.10	38	0.73***
Support Worker	T-R	26	0.73***	13	0.68*	24	0.91***
	I-R	31	0.20	12		26	0.66***
Sup. Worker & Other	T-R	25	0.90***	12	0.67*	24	0.91***
	I-R	33	0.34	16	-0.10	30	0.47**
Res. only	T-R	38	0.81***	33	0.72***	36	0.88***
	I-R	42	0.72***	36	0.61***	42	0.71***
Other only	T-R	37	0.87***	33	0.71***	37	0.74***
	I-R	42	0.61***	38	0.39*	41	0.46**
Res. & other	T-R	37	0.69***	33	0.79***	37	0.56***
	I-R	42	0.53***	37	0.36*	41	0.56***
Immediate	T-R	35	0.62***	29	0.29	37	0.95***
	I-R	41	0.60***	34	0.00	40	0.70***
Delay	T-R	35	0.73***	31	0.46**	37	0.81***
	I-R	42	0.57***	36	0.11	40	0.49**

Note: Highlighted results met the conditions for adequate reliability.
*$p<0.05$ **$p<0.01$ ***$p<0.001$

The frequency of immediate follow-through had adequate reliability for choices overall, but not for food choices individually, so this question was eliminated from further analyses.

(13, 14) Impact of Choice

Questions Thirteen and Fourteen of the Daily Choice Questionnaire examine the impact of choice (32%), on either the resident (29%), or on others (11%). The types of resident impacts examined were: *'change in routine'* (11%), *'new experience'* (1%), *'increased independence'* (18%), or generally *'negative'* impact (<1%). The types of impact on others were: *'interfered with the choices of others'* (1%), *'extra work for support workers'* (3%), *'less work for support workers'* (7%), or generally *'negative'* impact (0%). The two negative impact categories, and the *'interfered with the choices of others'* categories were not analysed due to low response rates.

Table 7.12: Results of test-retest (T-R) and inter-rater (I-R) reliability assessments for questions thirteen and fourteen on impacts of choice, of the Daily Choice Questionnaire.

IMPACT CHOICE ASPECTS		CHOICE AREA					
		OVERALL		FOOD		OTHER	
		N	*r*	*N*	*r*	*N*	*r*
No/Yes	T-R	37	0.95***	34	0.56**	37	0.95***
	I-R	42	0.78***	39	0.38*	42	0.68***
Resident	T-R	38	0.75***	34	0.74***	37	0.81***
	I-R	42	0.87***	37	0.63***	41	0.85***
Routine	T-R	38	0.83***	34	0.51**	36	0.73***
	I-R	42	0.67***	36	0.03	42	0.68***
Experience	T-R	37	0.82***	34	-0.03	37	0.84***
	I-R	42	0.81***	41	-0.03	41	0.87***
Independence	T-R	38	0.77***	33	0.81***	36	0.96***
	I-R	42	0.73***	39	0.51**	42	0.62***
Other	T-R	37	0.29	34		37	0.29
	I-R	42	0.89***	37	0.46**	42	0.87***
Extra work	T-R	37		33		36	
	I-R	42	0.67***	38	0.62***	42	0.62***
Less work	T-R	37	1.00***	33		37	1.00***
	I-R	42	0.83***	37	0.37*	42	0.76***

Note: Highlighted results met the conditions for adequate reliability.
*$p<0.05$ **$p<0.01$ ***$p<0.001$

Table 7.12 shows that the test-retest and inter-rater reliability of random sets of responses on the presence or absence of impact of choice were quite high (0.95, 0.78), as was the reliability of the frequency of resident impact (0.75, 0.87), although the test-retest reliability of the frequency of impact on others was low (0.29,0.89). Each *resident* impact type had adequate reliability, but most of the *other* impact types did not. For this reason, only the general *'resident'* and *'other'* categories of impact will be investigated further.

DISCUSSION

The analyses described above were intended to determine whether the questions asked in the Daily Choice Questionnaire were reliable and to reduce and refine the list of questions for analysis in the next two chapters.

Test-Retest Reliability

The purpose of determining the test-retest reliability was to see if support workers were responding consistently to the questions during the

course of the baseline assessment. Although low reliability may just indicate that there is a lot of variation between choice events, it may also indicate that the questions asked are not clear enough to elicit accurate and useful information.

It was apparent that this form of reliability was quite high for most of the questions asked, especially since the criteria used to determine adequacy were quite conservative, at least for choices overall. In particular, the core questions regarding resident experience of choice-making, the frequency of current opportunities for choice, whether there were limitations on the choice, whether or not the choice was responded to, and whether the choice was followed through, all reached sufficient test-retest reliability for choices overall, and for most choice areas individually.

However, there was less agreement regarding some of the details about who initiated the opportunity, the specific types of limitation, and the form of impact of choice on others. These questions were dealt with by merging options and relying on broader categories to increase reliability. For the questions addressing the form of communication for presenting choices, the types of influences on choice, and the means of responding to a choice opportunity, some of the specific options listed were responded to at such a low rate that these were eliminated, leaving a smaller number of alternatives for further examination.

For some of the more peripheral questions however, there was even greater variability. Although the reliability was adequate for choices overall, for the questions regarding whether options were in view, the number of options offered, and the timing of the follow-through of choice, the reliability for food choices was so low that these questions were eliminated from further analyses.

However, for the questions regarding the emotional responses of the residents and the reactions of the support workers, it was interpretation of meaning which put the questions into doubt. Both had initially included a *'no'* category, which in reality is meaningless as there is always some form of response or reaction even if it is neutral. In each case when the *'no'* category was merged with the neutral categories, more

than 95% of responses were accounted for, leaving very few alternative responses to investigate. Responses to these questions therefore add very little information to any investigation, and will thus be excluded from further analyses.

Inter-Rater Reliability

Inter-rater reliability was intended to assess whether different support workers responded in similar ways to the questions on the Daily Choice Questionnaire, as the evaluation of the training programme discussed in Study Four relies on the report of a range of different support workers.

As with the test-retest reliability, many of the questions had adequate inter-rater reliability. The main exceptions were the questions about the presentation of options, the emotional response of the resident, the reaction of the support worker, and the timing of follow-through of the choice. This low reliability led to the exclusion of these questions from further analyses. Another exception was the frequency of follow-through of choice responses, however the reconstructed agent-of-follow-through categories were quite reliable so this question was retained.

Nozaki and Mochizuki (1995) found that the option selected in a choice opportunity appears to co-vary with the social partner. This suggests that support workers may influence choices in different ways and thus inter-rater reliability might be expected to be low. Despite this the inter-rater reliability for many of the aspects of choice examined was adequate and thus averaging support worker responses appears reasonable.

Comparison of Daily Choice Areas

Although there was some variation between *food* and *other* daily choice areas in both forms of reliability, at least 50% of choice aspect options in each choice area had adequate test-retest reliability (Table 7.13). This was not the case with the inter-rater reliability for food choices, however, it was felt that there was sufficient reliability to examine the

impact of the training on *food* and *other* daily choice areas individually in Study Four as the criteria for reliability has been quite conservative.

Table 7.13 shows that the options with lowest test-retest reliability were the opportunity category 'other-initiated', and impact category 'other'. The 'other-initiated' choice opportunity category was retained as it is a core aspect of choice to be focussed on in the training in Study Four, while the 'other' impact option was retained to balance the 'resident' impact option. However, as a result of the questionable reliability of these categories, any conclusions based on these options should be viewed with caution.

Table 7.13: Summary of test-retest and inter-rater reliability for the revised list of questions from the Daily Choice Questionnaire.

CHOICE ASPECTS	RELIABILITY					
	Test-Retest			Inter-Rater		
	Overall	Food	Other	Overall	Food	Other
Stage A: OPTION RECOGNITION						
(1) Opportunities for Choice						
No/Yes	0.95	0.74	0.88	0.90	0.59	0.84
Other-initiated	0.34	0.24	0.40	0.67	0.40	0.57
Resident-initiated	0.90	0.64	0.87	0.85	0.52	0.77
(2) Choice Presentation						
Speech	0.88	0.62	0.60	0.62	0.20	0.20
Real objects	0.72	0.79	0.96	0.75	0.71	0.66
Gestures	0.76	0.95	0.80	0.02	-0.07	0.62
Stage B: EVALUATION AND SELECTION						
3) Limitations on Choice						
No/Yes	0.90	0.57	0.85	0.75	0.49	0.71
Resident	0.83	0.64	0.85	0.83	0.51	0.77
Environment	0.78	0.47	0.87	0.61	0.09	0.53
(4) Responses to Choice						
No/Yes	0.86	0.52	0.85	0.63	0.24	0.31
Action	0.83	0.62	0.80	0.50	0.11	0.48
Vocalisation	0.80	0.68	0.87	0.80	0.79	0.77
Gesture	0.68	0.47	0.47	0.88	0.95	0.75
Stage C: ACTING ON THE SELECTION						
(5) Follow-Through of Choice						
No/Yes	0.55	-0.04	0.80	0.36	0.13	0.27
Resident only	0.81	0.72	0.88	0.72	0.61	0.71
Other only	0.87	0.71	0.74	0.61	0.39	0.46
Resident & Other	0.69	0.79	0.56	0.53	0.36	0.56
(6) Impact of Choice						
No/Yes	0.95	0.56	0.95	0.78	0.38	0.68
Resident	0.75	0.74	0.81	0.87	0.63	0.85
Other	0.29		0.29	0.89	0.46	0.87
TOTAL	95%	70%	85%	95%	40%	75%

Notes: Total refers to the percentage of possible options that had adequate reliability.
Highlighted results met the conditions for adequate reliability.

Bold - $p<0.05$ Red - $p<0.01$

CONCLUSION

As a result of the elimination of questions, and merging of responses due to the reliability analyses completed in this chapter, the revised list of questions for investigation in Studies Three and Four is presented in Table 7.14. The question on experience was also retained but will be one of the resident characteristic independent variables in the next chapter rather than a dependent variable. This question differed from the others as it was not about the current choice, but about more general experience in the specific area.

Table 7.14: Revised choice aspect questions from the Daily Choice Questionnaire.

	QUESTION		OPTIONS
	Stage A: OPTION RECOGNITION		
1	Did the person have an opportunity to make a choice in this area during the current shift?		**NO**
	If YES, what form did the opportunity take?	2(a/b)	Opportunity was initiated by the **resident**
		2(c)	Presented **explicitly** by another
2	Which form(s) of communication were used to present the choice opportunity?	3(a)	**Real objects**
		3(e)	**Speech**
		3(d)	**Gestures**
	Stage B: EVALUATION AND SELECTION		
3	Were there any limitations on the person's choice?		**NO**
	If YES, which limitations affected the person's choice?	6(a-d,i)	**Resident**
		6(e-h,j)	**Environment**
4	Did the person communicate a response to the choice opportunity?		**NO**
	If YES, what form of communication was used?	9(a)	**Action**
		9(b)	**Vocalisation**
		9(c)	**Gesture**
	Stage C: ACTING ON THE SELECTION		
5	Was the choice followed through with?		**NO**
		11(a)	**Resident only**
		11(bc)	**Other only**
		11(a)/11(bc)	**Resident and Other**
6	Did the choice opportunity have an impact?	13(a)/14(a)	**NO**
		13(b-e)	**Resident**
		14(b-e)	**Other**

The outcome of this study is an apparently reliable set of questions which can be used to assess the impact of a training program promoting choice-making for adults with intellectual disabilities. The questions examine both the behaviour of the residents and their support

workers with regard to choice, and enable the issue of generalisation of training from *food* to *other* areas of daily choice to be examined.

Chapter Eight

STUDY THREE – INFLUENCES ON DAILY CHOICE

INTRODUCTION

The major purpose of this study is to answer the second of the four key questions of this thesis: what influences choice? There are two basic reasons for asking this question. Firstly, it is important to determine whether choice is influenced by characteristics which are malleable or not. In the context of this thesis malleable means potentially changeable through an intervention to improve choice. Identification of malleable influences on choice can then be used to develop more effective training interventions. Secondly, characteristics influencing choice, whether malleable or not, need to be controlled when determining groups to evaluate various experimental interventions designed to increase choice. This will enable differences between groups to be attributed to the intervention that the groups participate in. An additional purpose of this study is to thoroughly describe the resident and support worker samples being examined so that results of the subsequent training study can be interpreted accurately and generalisations are only made to comparable populations (Parmenter, 1990).

The basic intention of this study was therefore to determine in what ways the baseline daily choice-making of people with an intellectual disability was influenced by the characteristics of the residents themselves, the characteristics of the environment generally, and of the support workers in particular. These are the three areas identified by Stancliffe (1991) as being important influences on the availability of choice, the type of choices presented, and the way in which decisions were made. Stancliffe and Parmenter (1999) emphasise the importance of understanding how these characteristics interact to influence the amount of choice exercised by people with an intellectual disability. It is

not sufficient to examine the resident characteristics in isolation as Parmenter (1990) indicated that environmental factors can also influence how a person behaves and thus influence how severe their disability is perceived to be.

Resident Characteristics

Resident choice behaviour is thought to be affected by poorly developed skills which can limit access to free choice, and recognition of rights and responsibilities, which can result in residents making choices to please staff or handing over the major decision-making role.

Many researchers have identified a strong relationship between individual differences in intellectual functioning and adaptive behaviour and choice (Kishi, Teelucksingh, Zollers, Park-Lee & Meyer, 1988; Stancliffe, 1997). It is expected that these characteristics will strongly influence the behaviours described above. Communication skills were also identified by Stancliffe (2001) as important in facilitating choice which can be aided by the use of photographs and pictures.

Previous choice making experience has also been identified as a limitation on opportunities for choice, and the skills and capabilities for choice making by people with intellectual disability (Jenkinson, 1999; Rawlings, Dowse & Shaddock, 1995). As major life decisions regarding such things as place of residence, living companions and employment are usually less available than more routine choices such as what to eat and what to wear (Kishi, Teelucksingh, Zollers, Park-Lee & Meyer, 1988; Parmenter, Briggs & Sullivan, 1991), the impact of both daily and major-life choice experience will be examined.

Research had also consistently shown that differences in living arrangements are related to choice with those living in the community exercising more choice than the residents of institutions (Emerson & Hatton, 1996). In this study only the residents of group homes will be examined, however, the impact of their residential history on current choice behaviour will be assessed. This is consistent with Jenkinson's 1999 suggestion that decision-making be explored in relation to both past and present life experiences.

In summary resident characteristics selected as independent variables in this study: age, gender, the reported level of intellectual disability and adaptive behaviour, the presence of a physical disability, communication skills, experience in making both daily and major life choices, and certain aspects of previous residential history.

Environmental Characteristics

Stancliffe (1991) suggests that one of the most relevant environmental characteristics is group living and the need for consensus or compromise. Shaddock, Rawlings and Guggenheimer (1993) also indicated that the dynamics of group living would be a major influence on the extent and type of choices available. Therefore the number of residents in the household may be an important influence on choice behaviours.

In 2001 Stancliffe also indicated that studies are needed to examine specific features of the living environment and account for variability in personal control among settings of the same type. In line with this statement the current study only examines group home settings and assesses the impact of degree of normalisation on choice behaviours. Normalisation of the residence may provide an indication of the availability of choice opportunities within the environment (Zilber, 1994).

The impact of household routine will also be examined in the form of the temporal rhythm of the residence by recording the time of day, and day of the week, that the various choices take place. Rawlings, Nye and Shaddock (1994) concluded that routine may restrict choice-making to a greater extent than had previously been acknowledged by other research. Furthermore, Stancliffe, Abery and Smith (2000) indicated that modifying daily routines to make them more flexible and individualised would support personal control.

Support Worker Characteristics

Staff behaviour believed to relate to choice behaviour includes the use of prompts ranging from instruction to suggestions or reminders, modelling directive behaviour, identification and explanation of

consequences, and overruling residents on the grounds of duty of care due to financial, health or safety implications.

Support workers who feel relatively good about their jobs, their colleagues at work, and the organisation they work for, have been found to be more likely to contribute to endeavours that promote quality outcomes for the individuals they serve (Ford & Honnor, 2000). It was believed therefore, that the level of support worker job satisfaction might impact on the various aspects of resident choice behaviour. Shaddock (1994) also suggested that the inside knowledge of staff about residents is very important particularly in relation to the atypical or idiosyncratic ways that the person communicates. The inside knowledge of staff may also influence the acceptance or rejection of choice responses that the support worker 'knows' that the resident will not like the consequences of (Shaddock, Rawlings & Guggenheimer, 1993). Other staff characteristics identified by Stancliffe, Abery and Smith (2000) as important influences on resident's control included attitudes, skills and knowledge. These are in turn potentially influenced by support worker age, gender, experience and training.

The final list of support worker characteristics that are expected to impact on these behaviours and the way that they support resident choice was thus: support worker age and gender, industry experience and training, familiarity with the residents, job satisfaction, previous participation in choice workshops, as well as a rating of how successful the support worker feels that training in choice-making will be.

The dependent variables in this study are the six aspects of choice behaviour identified in the previous study, as measured by the baseline responses to the refined Daily Choice Questionnaire. These describe specific resident and support worker behaviours in the three basic stages of choice: *Option Recognition*, *Evaluation and Selection*, and *Acting on the Selection*. Although this results in a considerable number of analyses the Daily Choice Questionnaire is used in this examination rather than a simple measure of choice availability so that factors relevant to particular

aspects of choice can be determined. This will assist in determining avenues for improving choice at each stage of choice and the development of more detailed training programmes than would a focus on a single aspect of choice behaviour.

Hypotheses

The hypotheses in this study relate to the general categories of characteristics and whether the aspect of choice behaviour is expected to predominantly involve the resident, the environment, or the support worker. Hypotheses are summarised in Table 8.1.

Table 8.1: Summary of the hypotheses regarding the influence of resident, environment and support worker characteristics on each of the six aspects of choice behaviour (✓=predicted influence).

CHOICE ASPECTS	CHARACTERISTICS		
	Resident	Environment	Support Worker
Stage A: OPTION RECOGNITION			
(1) Opportunities for Choice			
No/Yes	✓	✓	✓
Resident-initiated	✓		
Other-initiated		✓	✓
(2) Choice Presentation			
Speech	✓		✓
Real objects	✓		✓
Gestures	✓		✓
Stage B: EVALUATION AND SELECTION			
(3) Limitations on Choice			
No/Yes	✓	✓	✓
Resident	✓		
Environment		✓	✓
(4) Responses to Choice			
No/Yes	✓		
Action	✓		
Vocalisation	✓		
Gesture	✓		
Stage C: ACTING ON THE SELECTION			
(5) Follow-Through of Choice			
No/Yes	✓	✓	✓
Resident only	✓		
Other only			✓
Resident & Other	✓		✓
(6) Impact of Choice			
No/Yes	✓		✓
Resident	✓		
Other			✓

Stage A: OPTION RECOGNITION

(1) Opportunities for Choice

Table 8.1 shows that it is hypothesised that opportunities for daily choice-making will be influenced by all three types of characteristic: resident, environment and support worker. Resident-initiated opportunities will be predominantly determined by resident characteristics while the frequency of other-initiated opportunities for choice will be determined by both environmental and support worker characteristics.

In particular opportunities generally will decrease with increasing intellectual disability level, and increase with increasing communication skills and adaptive behaviour. It is also hypothesised that other-initiated choice opportunities will be more frequent than resident-initiated choice opportunities for those with lower skill levels. Those living in more normalised residences are expected to have more choice opportunities, as will those whose support workers have more training and experience. More opportunities for choice are anticipated on weekends and afternoons when fewer commitments enable greater flexibility of routines, than on weekdays and mornings.

(2) Choice Presentation

The form of communication used to present choice other-initiated choice opportunities is expected to be influenced by both resident and support worker characteristics. Residents with greater ability are expected to be offered more choices using speech than real objects. It is also predicted that support workers with more training will make greater use of real objects to present choice opportunities.

Stage B: EVALUATION AND SELECTION

(3) Limitations on Choice

In the second stage of choice making it was hypothesised that the frequency of choices that were limited would be influenced by all three groups of characteristics, resident limitations particularly influenced by resident characteristics and environmental limitations influenced by both the environment and the support worker.

In particular more limitations, particularly those relating to the environment, were expected on the choices of those in less normalised houses. There would be more resident limitations for those with lesser ability than the more able residents, but there may also be more environmental limitations when support workers have less experience and training. Choices were also expected to be more limited in the mornings and on weekdays due to the greater restrictions of time and commitments.

(4) Responses to Choice

It was hypothesised that communication of a response to a choice opportunity was most likely to be influenced by resident characteristics such as general ability and communication skills. Previous resident experience in making choices was expected to increase the likelihood of response to a given opportunity. Greater adaptive behaviour would probably also result in more choices being responded to simply through action. However as responses were being reported by support workers, familiarity with the resident and their communication style may also influence the rated frequency of response to choice opportunity.

Stage C: ACTING ON THE SELECTION

(5) Follow-Through of Choice

All three types of characteristic were expected to be involved in the frequency of follow-through of a choice. Resident characteristics contributing to resident involvement in follow-through either alone or with assistance, and support worker characteristics would contribute to support worker involvement in follow-through.

As normalisation supports participation in everyday choices, houses with higher normalisation ratings would be expected to promote the involvement of residents in following through with their choice, and follow-through would be more frequent on weekends and afternoons when routine is less restricted.

(6) Impact of Choice

Frequency of impacts generally is expected to be influenced by both resident and support worker characteristics. More frequent resident

impacts of choice might be expected for residents with lesser ability or experience in making choices. Less support worker experience or training may also result in greater frequency of impacts of choice on others.

METHOD

Participants

The participants in this study were the 43 residents, and the 43 of the 58 support worker participants involved at baseline, from the eleven houses recruited for the purposes of the training study reported in Chapter Nine. The houses were described in detail in the previous chapter and the characteristics of the resident and support worker participants are elaborated below.

Procedure

Data for the independent variables were collected prior to completion of the Daily Choice Questionnaire through either self-report, house manager responses on behalf of the residents, or completion of specific instruments. Characteristics and details of their collection are described more fully below. Responses to the Daily Choice Questionnaire analysed in this study were collected according to the procedure described in the previous study.

Variables

Dependent Variables

The dependent variables in this study were the responses to the six aspects of choice behaviour from the Daily Choice Questionnaire (Appendix 2.1) identified in Study Two. The selected options for each choice behaviour aspect are presented in Table 8.2.

Table 8.2: Summary of the six aspects of choice questions from the revised Daily Choice Questionnaire to be used as dependent variables.

CHOICE ASPECT	OPTIONS				
Stage A: OPTION RECOGNITION					
(1) Opportunities for Choice	No	Resident-initiated			Other-initiated
(2) Choice Presentation	Speech	Real Objects		Gesture	Signing
Stage B: EVALUATION AND SELECTION					
(3) Limitations on Choice	None		Resident		Environment
(4) Responses to Choice	None	Action	Vocalisation	Gesture	Aid
Stage C: ACTING ON THE SELECTION					
(5) Follow-Though of Choice	None	Resident only		Other only	Resident & Other
(6) Impact of Choice	None		Resident		Other

For each of these options a percentage was calculated representing the proportion of choices in which the option was selected out of the number of times that the question was answered. The procedure for calculating these percentages is described more fully in the analyses section below. The combined total of the percentages for the options for each of *opportunity*, *responses*, or *follow-through* was 100%. This was not the case for the other aspects of choice behaviour as those questions permitted the indication of more than one alternative.

Resident Characteristic Independent Variables

In order to assess the relationship between resident characteristics and the different aspects of choice, residents were divided into two or three groups for each resident characteristic. These groups were based on categories for nominal variables such as gender and presence of physical disability, while for continuous variables such as age or time lived in current residence, residents were divided into three, roughly equal groups according to the variable value. These characteristics fall into four categories: personal, ability, choice experience, and residential history. These categories are described in more detail below, with the score ranges where relevant (Table 8.3).

Table 8.3: Summary of resident characteristic groups.

CHARACTERISTIC	GROUPS			*N*
PERSONAL				
Age	Younger (20-33 years)	Medium (34-48 years)	Older (49-76 years)	
	15 (35%)	12 (28%)	16 (37%)	43
Gender	Male		Female	
	16 (37%)		27 (63%)	43
ABILITY				
Intellectual Disability	Mild 1	Moderate 2	Severe 3	
	11 (28%)	21 (54%)	7 (18%)	39
Physical Disability	No		Yes	
	27 (64%)		15 (36%)	42
Adaptive Behaviour - SIB (307-555)	Low 323-426	Medium 428-466	High 470-504	
	10 (23%)	17 (40%)	16 (37%)	43
Communication Skills - CASP	Low	Medium	High	
	16 (37%)	15 (35%)	12 (28%)	43
CHOICE EXPERIENCE				
Daily Choice Experience (23-100%)	Low (23-64%)	Medium (65-95%)	High (96-100%)	
	14 (33%)	14 (33%)	15 (34%)	43
Major Life Choice Experience (0-2)	Low (0-0.56)	Medium (0.60-1.00)	High (1.10-1.80)	
	12 (32%)	13 (34%)	13 (34%)	38
RESIDENTIAL HISTORY				
Period of Residence (5-48 months)	Short (5-15 months)	Medium (16-30 months)	Long (31-48 months)	
	12 (31%)	12 (31%)	15 (38%)	39
Institutionalisation	No		Yes	
	7 (16%)		36 (84%)	43

Notes: Where appropriate the value ranges for each group are included.
Numbers indicate the number of residents in each group, with the percentage of total residents in brackets.

Personal

Basic demographic data on resident age and gender were collected using the form in Appendix 3.1. This form was completed by the house manager of each residence. These characteristics are considered non-malleable as they cannot be manipulated.

Ability

A number of different measures of resident ability were collected including the degree of intellectual disability, the presence of a physical disability, an adaptive behaviour skills score, and a communication skills rating.

Intellectual Disability

As level of intellectual disability is very difficult to measure due to the varying definitions and rating criteria, it was decided to simply use a rating by the house manager on a scale of mild-1, to severe-5. As the frequency of the extreme ratings was low, ratings 1 and 2, and 4 and 5 were merged leaving three categories. Although the expression of disability and consequent IQ ratings have been shown to change over time due to influences such as education and changes in circumstances (Clarke and Clarke, 1974), in the relatively short-term context of the current study, the rating of disability is considered to be non-malleable. This is because the rating is expected to be at least partially based on objective measurements related to funding levels that are unlikely to be reassessed during this period.

Physical Disability

The presence of a physical disability was indicated by the house manager using the form in Appendix 3.1. The specific types of physical disabilities reported included: mobility problems (12%), wheel chair bound (5%), visual impairment (7%), cerebral palsy (7%), hearing impairment (2%), and unspecified (2%). Physical disability is a non-malleable characteristic.

Adaptive Behaviour (SIB)

The Scales of Independent Behaviour (SIB) from the Woodcock-Johnson Psycho-Educational Battery (Bruininks, Woodcock, Weatherman & Hill, 1985) were completed by residents in order to obtain a more objective measure of adaptive functioning. The SIB is a standardised, norm-referenced scale designed to assess and evaluate adaptive behaviour needed for independent functioning in home, school and community (Ilmer, Bruininks & Hill, 1988). It is composed of 14 subscales that are in turn grouped into four major clusters of adaptive behaviour: motor skills, social and communication skills, personal living skills and community living skills, and a broad independence score. It has been reported to be a useful tool for categorising subjects (Ilmer, Bruininks & Hill, 1988). As adaptive functioning ratings would vary as skills were

developed this characteristic is considered to be malleable although it is expected to remain relatively stable in the short-term.

For the broad independence score and each of the skill clusters, scores were divided into three groups containing approximately a third of the residents. The distribution of scaled scores for each group is presented in Table 8.4, with the number of residents in each group following in brackets. The final column in this table indicates the complete range of scaled scores possible for each skill cluster. The age equivalents of the scores for each group are also included below the score range.

Table 8.4: Score ranges, age equivalents, and frequency of members of each SIB subscale group (n=43).

SIB CLUSTERS	GROUP			POSSIBLE
	Low	Medium	High	RANGE
INDEPENDENCE	323-426 (10)	428-466 (17)	470-504 (16)	307-555
age equivalent	*0-3 2-11*	*3-1 6-4*	*6-9 10-11*	
Motor Skills	257-411 (14)	414-454 (15)	464-515 (14)	257-536
age equivalent	*<0-3 2-5*	*2-6 4-7*	*5-6 13-7*	
Social Interaction and Comm. Skills	338-430 (14)	431-460 (14)	462-503 (15)	289-555
age equivalent	*<0-3 2-3*	*2-4 4-10*	*5-1 10-10*	
Personal Living Skills	356-455 (14)	459-492 (15)	495-515 (14)	343-559
age equivalent	*0-5 4-1*	*4-5 9-5*	*9-10 12-7*	
Community Living Skills	339-408 (14)	411-452 (15)	454-514 (14)	339-571
age equivalent	*0-5 2-10*	*3-1 6-0*	*6-2 12-3*	

Note: Age equivalents are in years-months

Communication Skills

Communication skills were assessed by administering the Communication Assessment Profile for Adults with a Mental Handicap (CASP - Van der Gaag, 1988) to residents, with some assistance from a support worker where necessary. The CASP assessment was used to assign residents to one of three communication skills groups (Table 8.3). As with adaptive functioning, communication skills can vary over time and thus would be considered malleable but are expected to remain stable in the short-term.

Choice Experience

Two measures of resident choice experience were used: daily choice experience and major life choice experience. These are summarised in Table 8.3. Both of these characteristics are considered malleable although it will be daily-choice experience which will be directly addressed in the training in the following chapter.

Daily Choice Experience

Daily choice experience was measured as part of the Daily Choice Questionnaire. Support workers rated whether the resident had experience or not in specific choice areas each time they completed the questionnaire. Residents were assigned to one of three equal groups according to the overall percentage of choices the resident had experience in at baseline.

Major Life Choice Experience

The house manager also completed a questionnaire on major life choice involvement. This questionnaire was developed by Jenkinson, Copeland, Drivas, Scoon and Yap (1992), and examines opportunities for choice-making in various aspects of life such as living situation, health and vocation (Appendix 3.2). It consists of 10 questions, each of which can receive a score of 0 – "*No*", or 2 – "*Yes*", and a few can also receive a score of 1 – "*Sometimes*". A higher score indicates greater involvement in major life choices, such as who to live with, which doctor to go to, and where to work. Residents were allocated to one of three roughly equal groups according to major life choice score.

Residential History

Residential history was assessed using two measures, each of which were reported by the house manager on the form in Appendix 3a. These characteristics were the period of residence in the current house, and whether or not they had been institutionalised in the past (Table 8.3). Both of these measures are considered to be non-malleable in the context of this thesis as training will not alter any aspect of residence.

Environmental Characteristic Independent Variables

Number of Residents

Although it was intended to include the number of residents as one of the environmental characteristics in this study, ten of the eleven houses consisted of four residents thus there was an insufficient range of residence sizes to analyse.

Normalisation

The house manager from each house also completed May's (1985) adaptation of Gunzburg's Thirty-nine Steps Checklist (Gunzburg, 1973), which was used to rate each residence on degree of normalisation (Appendix 3.3). The checklist contains 30 questions that examine living practices in residential settings and is reported to have adequate reliability and validity (May, 1985). Each question can receive a score of 0, 1, or 2 with an increasing score indicating a greater degree of normalisation. Normalisation score is considered to be at least partially malleable as practices within the house can be altered even if the structure can not.

In order to assess the relationship between normalisation and the six aspects of choice behaviour selected (Table 8.2), residents were divided into three groups according to the normalisation score of the house in which they lived. Each group contained approximately one third of residents. The score ranges in each group and distribution of residents are presented in Table 8.5.

Table 8.5: Range of scores and number of residents in each of the three normalisation score groups.

CHARACTERISTIC	GROUPS			*N*
Normalisation (43-60)	Low (43-47)	Medium (48-53)	High (58-60)	
	10 (23%)	17 (40%)	16 (37%)	43

Temporal Rhythm

A further environmental independent variable was the time of day, and time of week, that the Daily Choice Questionnaire was completed. This was used to determine the impact of daily and weekly temporal rhythms on dependent choice measures. Nirje (1985), indicated that

normal rhythms of the day and week were also important aspects of normalisation. The questionnaire was intended to be completed on four mornings and four afternoons for each resident during the two weeks that the baseline was recorded. The actual response rates for each time of day along with the rate for the whole day are presented in Table 8.6, the total response rate was 90%.

Temporal rhythm itself can not be altered however the restrictiveness of routines may be influenced, therefore this characteristic is considered to be malleable.

Table 8.6: Baseline response rates for the Daily Choice Questionnaire for residents at different times and days.

DAY	Weekday			Weekend			All Days		
TIME	Range	Mean	%	Range	Mean	%	Range	Mean	%
Morning	0-3	1.95	98	1-2.	1.74	87	0-3	1.85	92
Afternoon	0-3	2.02	101	0-3	1.49	74	0-3	1.76	88
Whole Day	0-3	1.99	99	0-3	1.62	81	0-3	1.80	90

Notes: Range and Mean refer to the number of times the questionnaire was completed.
% - percentage of completed questionnaires compared to the two intended for each time combination.

Support Worker Characteristic Independent Variables

Basic demographic data on support workers' age, gender, qualifications, as well as various ratings of training, experience and job satisfaction was collected by self-report on the form in Appendix 3.4.

In order to assess the relationship between support worker characteristics and the six aspects of choice behaviour selected from the Daily Choice Questionnaire (Table 8.2), the support workers were divided into groups of two or three for each support worker characteristic. Groups were based on categories for nominal variables, while for continuous variables support workers were divided into three roughly equal groups according to the variable value.

These characteristics fall into five categories: personal, familiarity with residents, industry experience, job satisfaction, and choice knowledge and attitudes. These characteristics are described in more detail below, with the score ranges where relevant (Table 8.7).

Table 8.7: Summary of support worker characteristic groups.

CHARACTERISTIC	GROUPS			N
PERSONAL				
Age	Younger (19-28 years)	Medium (29-40 years)	Older (41-54 years)	
	16 (39%)	12 (29%)	13 (32%)	41
Gender	Male		Female	
	13 (30%)		30 (70%)	43
FAMILIARITY WITH RESIDENTS				
Work in Residence (1-60 months)	Short (1-6 months)	Medium (7-15 months)	Long (16-60 months)	
	13 (32%)	14 (34%)	14 (34%)	41
Hours Worked (15-40 hrs/wk)	Short (15-22 hrs/wk)	Medium (25-30 hrs/wk)	Long (32-40 hrs/wk)	
	10 (27%)	13 (35%)	14 (38%)	37
INDUSTRY EXPERIENCE				
Time in Industry (2-300 months)	Short (2-17 months)	Medium (18-48 months)	Long (50-300 months)	
	13 (32%)	14 (36%)	13 (32%)	40
Disability Course	No		Yes	
	8 (36%)		14 (64%)	22
JOB SATISFACTION				
Job Satisfaction	Satisfying	Neutral	Lacking	
	33 (83%)	7 (17%)	(0%)	37
CHOICE KNOWLEDGE/ATTITUDES				
Choice Workshop Attendance	No		Yes	
	29 (73%)		11 (27%)	40
Predicted Success of Choice Training	Very		Somewhat / Not at all	
	12 (34%)		23 (66%)	35

Notes: Where appropriate the value ranges for each group are included.
Numbers indicate number of support workers in each group, the percentage of total support workers, from the final column, is in brackets.

Personal

Personal characteristics consisted of support worker age and gender, both of which are considered to be non-malleable as they cannot be influenced by any training intervention.

Familiarity with Residents

Experience with the particular group of residents that the support worker was rating was measured by how long the support worker had been working in the residence in months, and the average number of hours the support worker worked each week. Each of these measures was grouped into three roughly equal categories (Table 8.7). In the context of this thesis these characteristics are considered non-malleable

as training will not influence the time the resident has or will spend in the house.

Industry Experience

Industry experience, experience in working with people with intellectual disabilities generally, was indicated by the period of time (in months) that the support worker had worked in the industry, and whether they had attended a course specifically on working with people with intellectual disabilities. In this case the course was generally run through Technical and Further Education (TAFE). These characteristics are described in Table 8.7. As with familiarity with residents, industry experience is considered to be non-malleable in the context of this thesis as the time the resident has worked in the industry will not be influenced by any training intervention.

Job Satisfaction

Support worker job satisfaction was simply rated on a three point scale which was labelled as satisfying, neutral, and lacking. None of the support workers indicated that they currently found their job lacking in satisfaction, leaving only two categories for comparison (Table 8.7). Job satisfaction is considered to be partially malleable as although organisational conditions can not be altered by training, there is the potential for influencing support worker motivation and effectiveness which may in turn impact on job satisfaction.

Choice Knowledge and Attitudes

Choice Workshop Attendance

Previously in Tasmania, the Disability Services resource team has provided workshops aimed at improving support workers' awareness of the rights of people with intellectual disabilities. They encourage support workers to recognise current limitations on choice, and to provide more choice opportunities. This approach is limited as the workshops are usually attended only once, they are for support workers only, and they examine general principles, not interventions for individual residents.

Previous attendance of support workers at one of these workshops was used as an independent variable to assess whether it influenced any of the six aspects of choice behaviour. This characteristic is not malleable in the context of this thesis as it refers to participation in the specific type of workshop run by Disability Services, that is, a general, one-off workshop for support workers only.

Predicted Success of Choice Training

Support workers were also asked to indicate on a three-point scale how successful they thought that training in choice making would be in improving resident's choice-making. The scale labels consisted of *'very'*, *'somewhat'*, and *'not at all'*, however these last two categories were merged as the response rate to *'not at all'* was quite low (Table 8.7). This characteristics is malleable and will be addressed in the development of the training to be reported in the next chapter.

Analyses

The analyses described below are repeated for each option of the six aspects of choice behaviour of the revised Daily Choice Questionnaire. Generally, one-way analyses were carried out to assess the relevance of resident, environmental, and support worker characteristics to the baseline measures of the six aspects of choice behaviour.

Resident Characteristics

For each option of the six aspect questions of the Daily Choice Questionnaire identified for further analyses in Study Two, a percentage was calculated for each resident, regardless of the support worker who responded. This percentage represented the proportion of occasions that the choice stage question was completed and the option was selected, regardless of the daily choice area.

As there were eight questions on each of the morning and afternoon questionnaires, and each questionnaire was to be completed four times for each resident during baseline, there were 64 potential opportunities for choice. However, as all four of each questionnaire was not completed in every case, the exact number of potential choice

opportunities may have been less. For example, for choice opportunity, the first aspect of choice behaviour, if the questionnaire was completed three times in the morning and 15 choice opportunities were identified, and the questionnaire was completed four times in the afternoon and 24 opportunities for choice were identified then the opportunity percentage would be 15+24=39 opportunities out of a potential (3+4)x8=56 choices, or 70%.

Similar calculations were made for each aspect of choice behaviour, however the potential total varied depending on the choice aspect. *Opportunity* and *limitation* were each calculated as a percentage of the total possible choices; *communication type* was reported as a percentage of other-initiated choice opportunities only; while *response*, *follow-through,* and *impact* were all calculated as percentages of choices when an opportunity was present. For simplicity, the y-axis in each figure will be labelled as 'Percentage' and the relevant aspect of choice that is described will be reported at the top of the figure.

Repeated measures analyses of variance were carried out on the resident percentages in order to determine whether there were any interactions between resident characteristics and different responses to the selected questions from the Daily Choice Questionnaire. One-way analyses of variance and Tukey tests were then completed in order to identify significant effects of resident characteristics on responses to individual options to the Daily Choice Questionnaire.

All analyses were carried out using a significance level of 0.01 in an attempt to compensate for the large number of analyses completed. In this section approximately 270 analyses, were completed to assess the effect of resident characteristics, of these 35 proved to be significant at the 0.01 level (an additional 18 analyses were significant at the 0.05 level). On the basis of a Type I error rate of 0.01, approximately 3 of the significant results would be expected to be due to chance, leaving a further 32, or approximately 91% of the significant findings, reflecting genuine psychological effects.

Environmental Characteristics

Normalisation

A similar series of analyses on the percentages relating to residents were used to assess the effect of normalisation, as for the resident characteristics. These consisted of repeated measures ANOVA, one-way analyses of variance, followed up with Tukey tests. A significance level of 0.01 was again used as 27 analyses were completed in this section.

Temporal Rhythm

One-way analyses of variance were completed on resident percentages in order to compare the responses to the two difference versions of the Daily Choice Questionnaire - morning and afternoon, and the responses on weekdays compared to weekends.

All analyses were carried out using a significance level of 0.01 in an attempt to compensate for the large number of analyses completed. In this section approximately 54 analyses were carried out, of these 3 proved to be significant at the 0.01 level (an additional 7 were significant at the 0.05 level).

Support Worker Characteristics

Support worker characteristics were analysed in the same way as resident characteristics, but in this case the percentages were calculated for each support worker, regardless of the resident they were responding about, for each of the options of the relevant choice aspect questions of the Daily Choice Questionnaire. Otherwise, percentages were calculated in the same way as those for resident characteristics, and represented the proportion of occasions that the choice stage question was completed and the option was selected, regardless of the daily choice area.

Support worker characteristic analyses were carried out in a similar way to the resident characteristics, but a mean intellectual disability score (on a five point scale) for the residents that the support worker had responded about was used as a covariate in order to compensate for differences in resident ability. In this chapter ANCOVA results will be

presented if the covariate proved to be significant, ANOVA results will be reported if the intellectual disability covariate was not.

As with the analyses on the other characteristics, all analyses were carried out using a significance level of 0.01 in an attempt to compensate for the large number of analyses completed. In this section approximately 302 analyses were carried out, of these 66 proved to be significant at the 0.01 level (an additional 5 were significant at the 0.05 level). On the basis of a Type I error rate of 0.01, approximately 3 of the significant results would be expected to be due to chance, leaving a further 63, or approximately 95% of the significant findings, reflecting genuine psychological effects.

RESULTS

Independent Variable Correlations

Pearson correlations within characteristic categories were calculated in order to assist with the interpretation of results in the body of this study. Correlations were considered adequate if the correlation coefficient was at least 0.5 and reached a significance of 0.01. Cohen (1992) considered that a coefficient of 0.5 was a strong correlation.

Resident

None of the correlations between the resident characteristics: age, gender, period of residence, institutionalisation, or time in institution and any of the other resident characteristics, was considered adequate. Intellectual disability was negatively correlated with SIB independence score (Table 8.8), SIB social interaction and communication skills, and SIB community living skills, as well as daily choice experience (0.52). Physical disability was correlated with SIB motor skills scores only (-0.61).

The SIB independence score and each of the four SIB scales were significantly correlated with each other. These correlations and the correlations of the SIB scales with level of intellectual disability, CASP score, and both daily and major life choice experience scores are presented in Table 8.8. Despite many of the correlations between SIB

cluster scores and major life choice experience reaching significance, the *r* values were not sufficient to be recognised as an adequate correlation except in the case of the community living skills cluster.

Table 8.8: Significant correlations between SIB independence score and SIB clusters and selected resident characteristics.

SIB CLUSTERS	SIB CLUSTERS				Level of Intellectual Disability	CASP Score	Daily Choice Exper.	Major Life Choice
	Motor	Social Interaction	Personal Living	Comm. Living				
N	43	43	43	43	43	43	43	38
INDEPENDENCE	0.90***	0.90***	0.95***	0.90***	-0.51**	0.79***	0.61***	0.49**
Motor		0.66***	0.90***	0.67**	-0.29	0.57***	0.53***	0.37*
Social Interaction			0.81***	0.90***	-0.58***	0.87***	0.59***	0.49**
Personal Living				0.76***	-0.47**	0.67***	0.60***	0.44**
Community Living					-0.57***	0.85***	0.51**	0.52**

Note: Highlight - Adequate correlations: *r* of at least 0.50, significance level of $p<0.01$
*$p<0.05$ **$p<0.01$ ***$p<0.001$

The CASP score was positively correlated with SIB independence score and each of the SIB cluster scores (Table 8.7), as well as daily choice experience (0.58). Daily choice experience was negatively correlated with level of disability (-0.52), and positively correlated with the SIB independence score and each of the SIB cluster scores (Table 8.8). Surprisingly, major life choice and daily-living choices were not correlated with each other (0.16).

Environmental

Although the correlation between normalisation score and the resident characteristics: past institutionalisation (-0.46), SIB motor skills (0.41), and major life choice score (0.44), all reached significance, the *r* values were not high enough to indicate adequate correlations.

Support Worker

Support worker and resident characteristics could not be directly compared as they were based on different data sets. There were no significant correlations between any support worker characteristics.

Stage A: OPTION RECOGNITION

(1) Opportunities for Choice

Support workers responded 'yes' to whether residents had an opportunity for choice during their current shift (67%) significantly more often than they responded 'no'. They also indicated whether the choice opportunities were *resident-initiated* (46%) or offered by *another* (21%). There was a significant effect of opportunity type (resident-initiated versus other-initiated): $F(1,42)=24.80$, $p<0.001$, on the frequency of choice opportunity, due to a larger number of *resident* rather than *other-initiated* opportunities. Daily choice experience was the only characteristic with a significant interaction with opportunity type (described in detail below).

The results of one-way analyses of variance on the effect of resident, environmental and support worker characteristics on the proportion of choice opportunities of each opportunity type are presented in Table 8.9. Analyses of covariance were not used for the *other-initiated* opportunity group as intellectual disability level was not significant as a covariate for any of the support worker characteristics.

Table 8.9: Results of one-way ANOVAs on the impact of resident and environmental characteristics, and ANCOVAs on support worker characteristics controlling for the intellectual disability of residents, on the percentage of various *types of opportunity for choice.*

CHARACTERISTICS	OPPORTUNITY TYPE					
	None		Resident-Initiated		Other-Initiated	
	covariate *F*	*F*	covariate *F*	*F*	*F*	
RESIDENT						
Age		$F(2,40)$ 0.19		$F(2,40)$ 1.95	$F(2,40)$ 0.97	
Gender		$F(1,41)$ 0.98		$F(1,41)$ 2.85	$F(1,41)$ 0.31	
Intellectual Disability		$F(2,36)$ 6.63**		$F(2,36)$ 5.56**	$F(2,36)$ 0.74	
Physical Disability		$F(1,40)$ 2.10		$F(1,40)$ 1.22	$F(1,40)$ 0.59	
Adaptive Functioning		$F(2,40)$ 12.79***		$F(2,40)$ 10.56***	$F(2,40)$ 0.44	
Communication Skills		$F(2,32)$ 1.08		$F(2,32)$ 0.77	$F(2,32)$ 1.53	
#Daily Choice Exp.		$F(2,40)$ 67.40***		$F(2,40)$ 27.13***	$F(2,40)$ 1.30	
Major Life Choice		$F(2,35)$ 2.92		$F(2,35)$ 2.37	$F(2,35)$ 0.79	
Period of Residence		$F(2,36)$ 2.43		$F(2,36)$ 1.41	$F(2,36)$ 0.45	
Institutionalisation		$F(2,41)$ 0.78		$F(2,41)$ 0.97	$F(2,41)$ 0.42	
ENVIRONMENT						
Normalisation		$F(2,40)$ 2.55		$F(2,40)$ 1.10	$F(2,40)$ **3.41***	
Day of Week		$F(1,42)$ 0.36		$F(1,42)$ 0.04	$F(1,42)$ 0.09	
Time of Day		$F(1,41)$ 7.72**		$F(1,41)$ 3.88	$F(1,41)$ 0.05	
SUPPORT WORKER						
Age	$F(1,33)$ 15.00***	$F(2,33)$ 0.49	$F(1,32)$ 13.83**	$F(2,32)$ 0.67	$F(2,38)$ 0.96	
Gender	$F(1,36)$ 13.06**	$F(1,36)$ 1.25	$F(1,35)$ 11.96**	$F(1,35)$ 0.02	$F(1,41)$ 3.51	
Work in Residence	$F(1,33)$ 10.03**	$F(2,33)$ 1.08	$F(1,32)$ 8.84**	$F(2,32)$ 1.02	$F(2,38)$ 0.05	
Hours Worked	$F(1,31)$ 10.67**	$F(2,31)$ 0.36	$F(1,30)$ 9.05**	$F(2,30)$ 0.03	$F(2,34)$ 0.10	
Industry Experience	$F(1,32)$ 13.49**	$F(2,32)$ 1.36	$F(1,32)$ 12.66**	$F(2,32)$ 1.13	$F(2,37)$ 1.70	
Disability Course	$F(1,17)$ 10.05**	$F(1,17)$ 2.37	NS	$F(1,19)$ 0.50	$F(1,20)$ 0.40	
Job Satisfaction	$F(1,33)$ 10.94**	$F(1,33)$ 0.41	$F(1,32)$ 9.43**	$F(1,32)$ 0.23	$F(1,38)$ 0.38	
Workshop Attendance	$F(1,33)$ 24.30***	$F(1,33)$ 9.32**	$F(1,32)$ 14.88**	$F(1,32)$ 1.45	$F(1,38)$ 2.56	
Success of Training	$F(1,29)$ 11.21**	$F(1,29)$ 0.69	$F(1,28)$ 10.05**	$F(1,28)$ 0.00	$F(1,33)$ 2.66	

Notes: ANOVAs were used for support worker characteristics if the covariate was not significant,
Highlight - characteristics with significant effects on choice *opportunity* to be elaborated in detail,
- characteristics with significant interaction with *opportunity type*.
NS-non significant
**p*<0.05 ***p*<0.01 ****p*<0.001

Resident

Intellectual Disability

There was a significant effect of intellectual disability level on the frequency of opportunities overall, and on the frequency of resident-initiated choices in particular (Table 8.9). In both cases Tukey tests showed that the effect was due to a significantly higher rate of opportunity for the mild group than for those in the severe intellectual disability group (Figure 8.1).

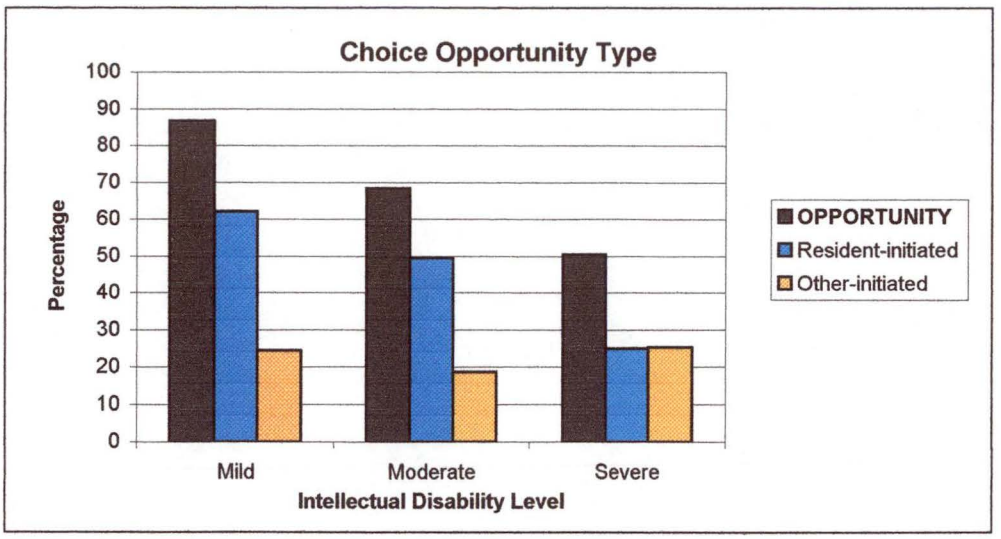

Figure 8.1: Impact of level of intellectual disability on the percentage of different types of *choice opportunity.*

Adaptive Behaviour (SIB)

As for the rating of intellectual disability, there was a significant effect of SIB independence group for both choice opportunities overall, and for resident-initiated choice opportunities (Table 8.9).

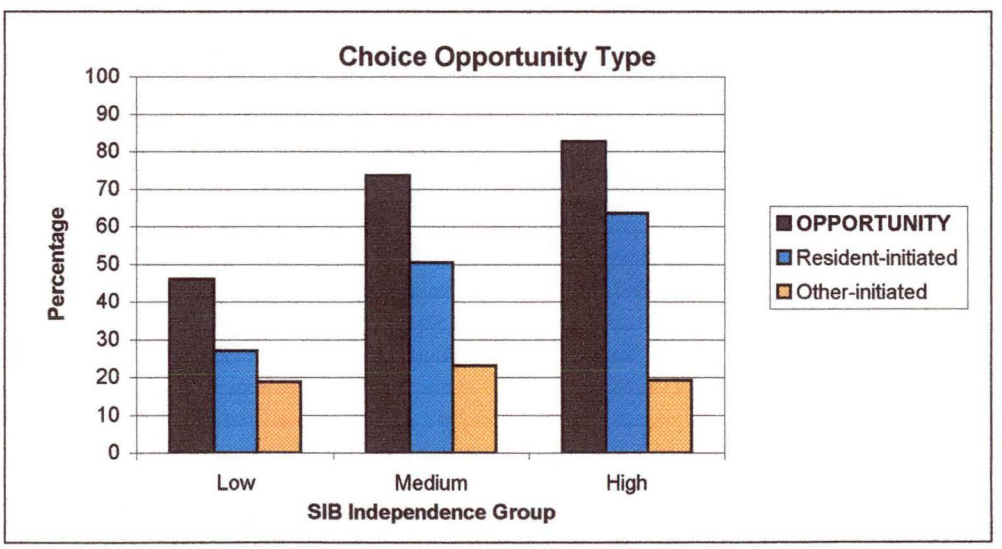

Figure 8.2: Impact of SIB independence group on the percentage of different choice *opportunity types.*

For choice opportunities overall there were significantly fewer opportunities available to those with low SIB independence scores than either of the higher SIB groups (Figure 8.2). For resident-initiated choices however, those with low SIB independence scores initiated fewer choices than those with high SIB scores only.

Table 8.10: One-way ANOVA and Tukey test results on the effect of adaptive functioning (SIB) cluster groups on the percentage of overall and resident-initiated *choice opportunities.*

SIB CLUSTERS	OPPORTUNITY TYPE							
	OPPORTUNITY				Resident-Initiated			
		SIB GROUP				SIB GROUP		
	F(2,40)	Low	Med.	High	*F*(2,40)	Low	Med.	High
INDEPENDENCE	12.79***	H M	L	L	10.56***	M H	L	L
Motor Skills	10.38***	H M	L	L	10.05***	M H	L	L
Social Interaction / Comm. Skills	5.43**	H		L	6.09**	H		L
Personal Living Skills	12.76***	M H	L	L	22.37***	M H	L H	L M
Community Living Skills	4.67*	H		L	2.97			

Note: Red letter - significantly different from group in column header at 0.01 level (**black** letters, 0.05 level).
*$p<0.05$ **$p<0.01$ ***$p<0.001$

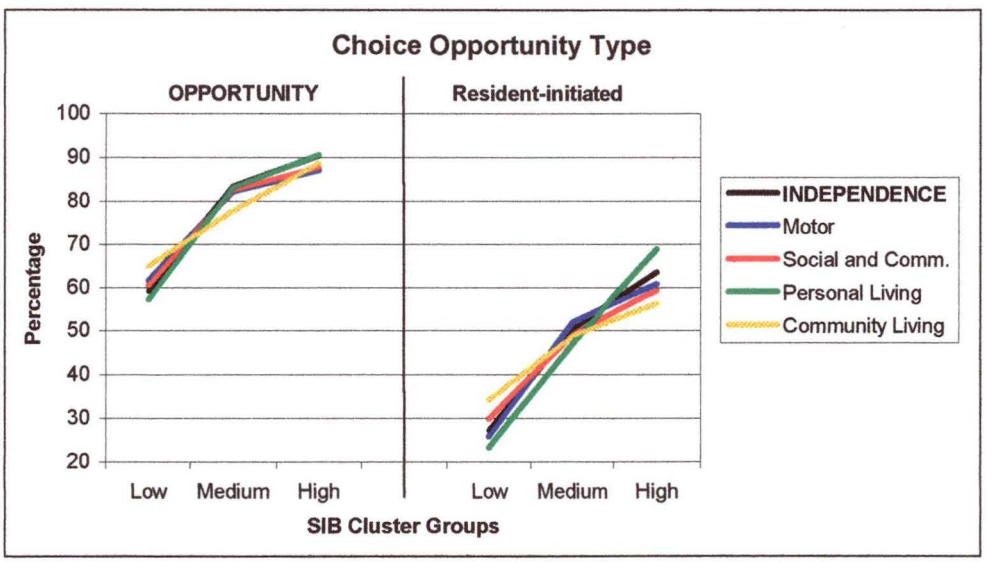

Figure 8.3: Impact of SIB independence cluster groups on the percentage of both general and resident-initiated *choice opportunities.*

Table 8.10 presents the results when the different SIB clusters were analysed for their impact on choice opportunity. This table shows that for all the skills clusters, barring community living skills, there was a significant difference between the low group and either the high, or both the medium and high SIB groups. In each case the low group had fewer opportunities for choice (Figure 8.3).

Daily Choice Experience

There was a significant interaction between daily choice experience group and opportunity type: $F(2,40)=6.99$, $p=0.002$, as well as an effect of opportunity type: $F(1,40)=30.53$ $p<0.001$, and an effect of daily choice experience group: $F(2,40)=67.40$, $p<0.001$. The interaction was probably the result of the significantly higher frequency of resident-initiated than other-initiated choice opportunities for the residents in the high daily choice experience group only: $F(1,14)=31.70$, $p<0.001$.

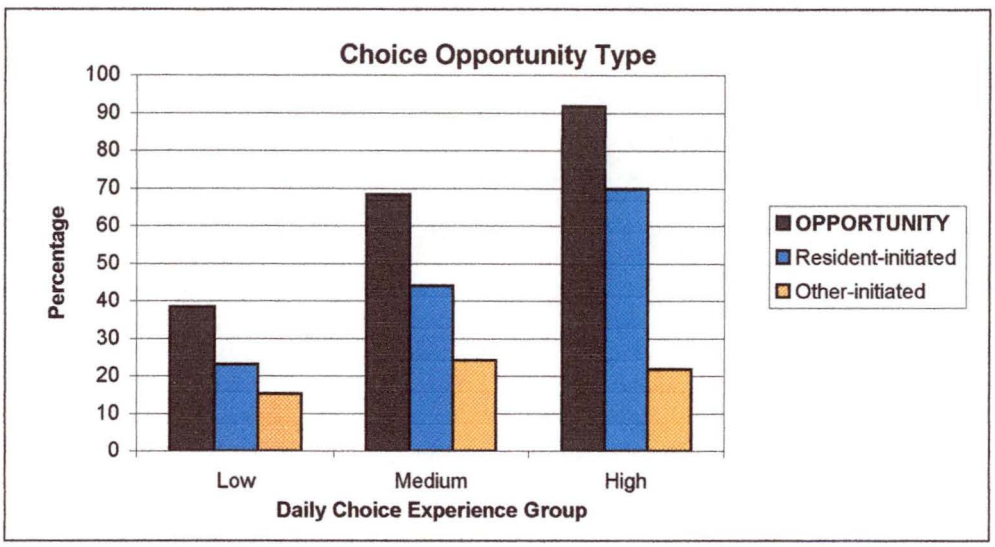

Figure 8.4: Impact of daily choice experience on the percentage of different choice *opportunity types.*

One-way ANOVA showed that there was also a significant effect of the daily choice experience group on the frequency of opportunities for choice generally, and resident-initiated choice opportunities in particular, but not for other-initiated opportunities (Table 8.9). Tukey tests showed that for both opportunities overall and resident-initiated opportunities individually there was a significant difference between each daily choice experience group and the other two. The more daily choice experience the resident had, the more opportunities they had for choice opportunities (Figure 8.4).

Environment

Time of Day

There was a significant effect of time of day on the frequency of choice opportunities (Table 8.9), due to residents having more opportunities for choice in the morning (71%) than the afternoon (64%).

Support Worker

Choice Workshop Attendance

A significant effect of previous attendance of support worker at a disability services choice workshop was found on the frequency of opportunities for choice when resident disability was controlled for (Table 8.9). Contrary to expectations, this was due to a higher rate of choice opportunity reported by support workers who had not attended the workshop (66%) than those who had (60%).

(2) Choice Presentation

Support workers were asked to indicate the form(s) of communication that were used to present each of the other-initiated choice opportunities: *speech* (68%), *real objects* (29%), *gestures* (13%), and *signing* (4%). These percentages exceed 100% as multiple forms of communication may be used for a single choice.

Table 8.11: Summary of the results of repeated measures ANOVA tests comparing the frequency of pairs of *communication forms* for presenting other-initiated choice opportunities.

COMMUNICATION FORM	COMMUNICATION FORM			
	Speech	Real object	Gesture	Signing
	$F(1,42)$	$F(1,42)$	$F(1,42)$	$F(1,42)$
Real Object	20.03***		7.59**	20.20***
Gestures	68.18***	7.59**		6.97*
Signing	108.41***	20.20***	6.97*	

*$p<0.05$ **$p<0.01$ ***$p<0.001$

There were also interactions between communication form and each of: SIB independence group, daily choice experience group, the time resident had lived in the residence, and support worker job satisfaction rating. These interactions are described below.

There was a significant difference between the four communication forms that were indicated by the support workers: $F(3,126)=40.94$, $p<0.001$, and a summary of significant pairs of communication forms is presented in Table 8.11. This table shows that the frequency of *speech* to present other-initiated choices was significantly higher than any other communication form, and that the use of *real objects* was significantly more frequent than everything other than *speech.*

Table 8.12 presents a summary of the impact of the different resident characteristics on the use of *speech* and *real objects* to present choice opportunities. There were no significant effects of any characteristics for the use of *gesture* or *signing* to present choices.

Table 8.12: Results of one-way ANOVAs on the impact of resident and environmental characteristics, and ANCOVAs on support worker characteristics controlling for the intellectual disability of residents, on the percentage of various *forms of communication* for presenting other-initiated choice opportunities.

CHARACTERISTICS	COMMUNICATION FORM							
	Speech				Real Objects			
	covariate *F*		*F*		covariate *F*		*F*	
RESIDENT								
Age			*F*(2,40)	0.05			*F*(2,40)	1.22
Gender			*F*(1,41)	1.40			*F*(1,41)	1.55
Intellectual Disability			*F*(2,36)	9.72***			*F*(2,36)	10.49***
Physical Disability			*F*(1,40)	0.26			*F*(1,40)	1.23
#Adaptive Functioning			*F*(2,40)	3.43*			*F*(2,40)	11.45***
Communication Skills			*F*(2,32)	0.20			*F*(2,32)	0.40
#Daily Choice Exp.			*F*(2,40)	10.84***			*F*(2,40)	9.59***
Major Life Choice			*F*(2,35)	1.71			*F*(2,35)	4.03*
#Period of Residence			*F*(2,36)	16.59***			*F*(2,36)	4.40*
Institutionalisation			*F*(2,41)	0.90			*F*(2,41)	0.16
ENVIRONMENT								
Normalisation			*F*(2,40)	2.01			*F*(2,40)	1.84
Day of Week			*F*(1,36)	0.32			*F*(1,36)	0.08
Time of Day			*F*(1,38)	0.65			*F*(1,38)	2.70
SUPPORT WORKER								
Age	*F*(1,27)	21.48***	*F*(2,27)	0.66	*F*(1,27)	42.12***	*F*(2,27)	2.86
Gender	*F*(1,30)	20.43***	*F*(1,30)	0.07	*F*(1,30)	36.76***	*F*(1,30)	0.84
Work in Residence	*F*(1,27)	12.68**	*F*(2,27)	0.48	*F*(1,27)	30.22***	*F*(2,27)	1.74
Hours Worked	*F*(1,26)	19.18***	*F*(2,26)	0.22	*F*(1,26)	31.81***	*F*(2,26)	0.10
Industry Experience	*F*(1,26)	24.40***	*F*(2,26)	2.97	*F*(1,26)	55.03***	*F*(2,26)	0.01
Disability Course	*F*(1,14)	12.34**	*F*(1,14)	2.51	NS		*F*(1,17)	4.52*
#Job Satisfaction	*F*(1,27)	12.06**	*F*(1,27)	1.77	*F*(1,27)	22.78***	*F*(1,27)	1.79
Workshop Attendance	*F*(1,27)	22.23***	*F*(1,27)	1.13	*F*(1,27)	33.10***	*F*(1,27)	0.11
Success of Training	*F*(1,23)	16.77***	*F*(1,23)	0.74	*F*(1,23)	34.51***	*F*(1,23)	0.55

Notes: ANOVAs were used for support worker characteristics if the covariate was not significant,
Highlight - characteristics with significant effects on *communication form* to be elaborated in detail,
- characteristics with significant interaction with *communication form.*
NS-non significant
***$p<0.05$ **$p<0.01$ ***$p<0.001$**

Resident

Intellectual Disability

There was a significant effect of intellectual disability on the frequency that both speech and real objects were used to present other-initiated choices to residents (Table 8.12). Significantly more choice opportunities were presented using speech for the mild intellectual disability group (95%) than the severe group (34%), but the moderate intellectual disability group (66%) was not significantly different from either. Real objects were used significantly less often to present choice

opportunities to those with a mild intellectual disability (13%) than to those with either a moderate (21%) or severe disability (67%).

Adaptive Behaviour (SIB)

Although there was no effect of SIB independence group: $F(2,40)=3.53$, $p=0.039$, there was a significant interaction between type of communication form used to present other-initiated choice opportunities and SIB independence group: $F(6,120)=5.55$. $p<0.001$. This effect was due to the lack of significant difference between the use of speech and real objects for the low SIB independence group only. Use of speech was significantly more frequent than other means of communicating a choice opportunity in all other cases for each SIB group (Table 8.13). For the low SIB independence group only, real objects were used significantly more frequently than signing to communicate a choice opportunity.

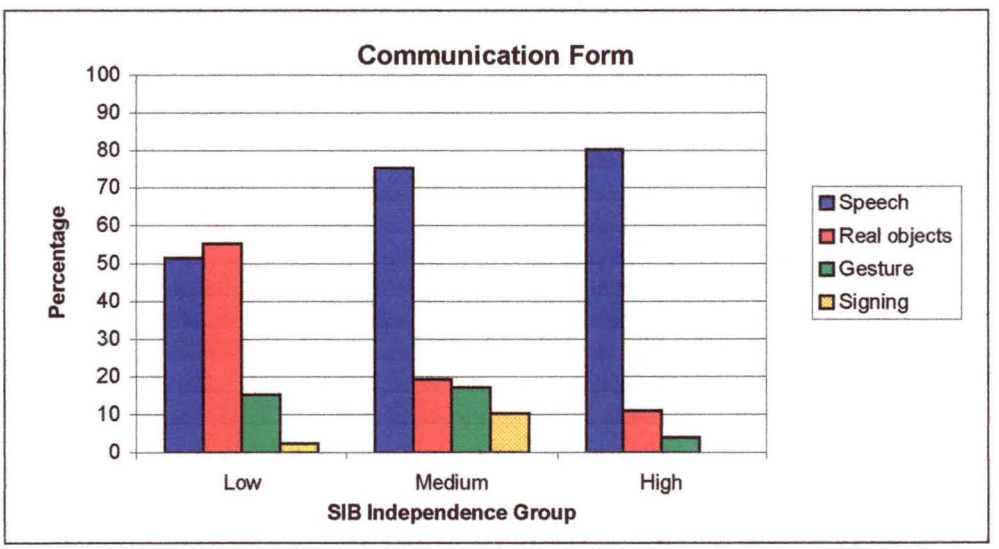

Figure 8.5: *Communication forms* for presenting choice opportunities to residents in different SIB independence groups.

Table 8.13: Results of one-way ANOVAs on the impact of SIB independence group on the percentage of various *forms of communication* for presenting choice opportunities.

COMMUNICATION TYPE	SIB INDEPENDENCE GROUP					
	Low		Medium		High	
	F		*F*		*F*	
All Communication Types	*F*(3,42)	**14.70*** **	*F*(3,42)	**15.01*** **	*F*(3,36)	**41.08*** **
Speech-Real Object	*F*(1,14)	0.08	*F*(1,14)	**18.43** *	*F*(1,12)	**38.97*** **
Speech-Gesture	*F*(1,14)	**13.31** *	*F*(1,14)	**20.85*** **	*F*(1,12)	**53.64*** **
Speech-Signing	*F*(1,14)	**42.85*** **	*F*(1,14)	**26.81*** **	*F*(1,12)	**60.33*** **
Real Object-Gesture	*F*(1,14)	**12.99** *	*F*(1,14)	0.04	*F*(1,12)	1.17
Real Object-Signing	*F*(1,14)	**40.83*** **	*F*(1,14)	0.87	*F*(1,12)	**5.45***
Gesture-Signing	*F*(1,14)	**5.13***	*F*(1,14)	1.40	*F*(1,12)	1.00

***p*<0.05 ****p*<0.01 *****p*<0.001

There was also a significant effect of SIB independence group on the use of *real objects* in other-initiated choice presentation (Table 8.12), which Tukey tests showed was due to a significantly higher use of *real objects* for the low SIB independence group, than the other two groups.

Table 8.14: Results of one-way ANOVA and Tukey tests on the effect of adaptive functioning (SIB) groups on use of *real objects* to present choice opportunities.

SIB CLUSTERS	SIB GROUP			
	F(2,40)	Low	Med.	High
INDEPENDENCE	**11.45*****	**H M**	**L**	**L**
Motor Skills	**7.90****	**H M**	**L**	**L**
Social Interaction / Comm. Skills	**7.28****	**H M**	**L**	**L**
Personal Living Skills	**12.13*****	**H M**	**L**	**L**
Community Living Skills	**11.23*****	**H M**	**L**	**L**

Note: Red letter - significantly different from group in column header at 0.01 level (**black** letters, 0.05 level).
***p*<0.05 ****p*<0.01 *****p*<0.001

When the different SIB scales and subscales were analysed for their impact on the use of *real objects* in the presentation of choice opportunities, the results in Table 8.14 were found. The table shows that in many of the scales there was a significant difference between the low and high, or low and both the medium and high SIB score groups. As for the SIB independence score, the greater the development of the skills, the less likely that choices were presented using *real objects* (Figure 8.6).

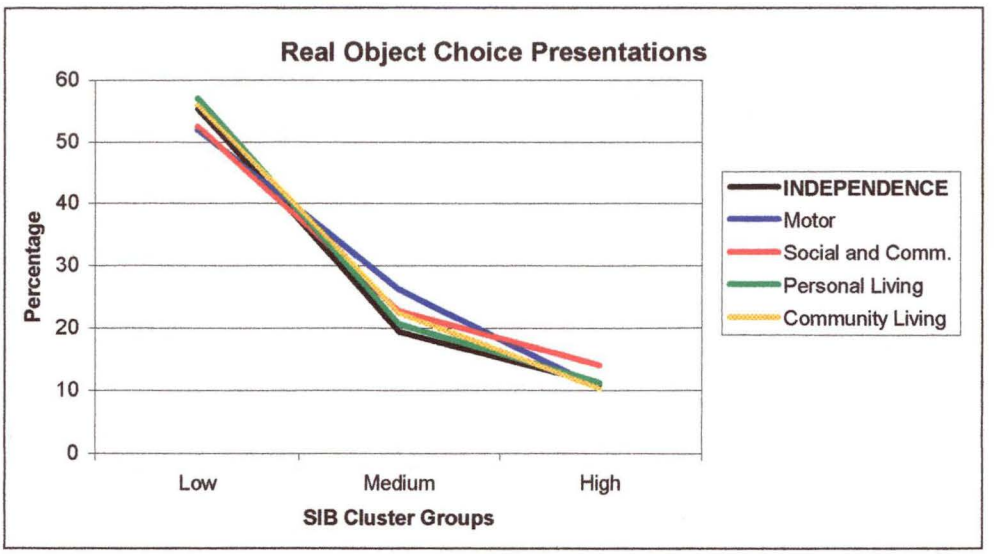

Figure 8.6: Impact of SIB independence cluster groups on the use of *real objects* to present other-initiated choice opportunities.

Daily Choice Experience

There was a significant interaction between daily choice experience group and the four communication forms used to present choice opportunities: $F(6,120)=8.36$, $p=0.002$, as well as an effect of communication form: $F(3,120)=54.06$, $p<0.001$, but no effect of daily choice experience group: $F(2,40)=2.54$, $p=0.092$.

Table 8.15: Results of one-way ANOVAs on the impact of daily choice experience group on the percentage of different *types of communication* for presenting choices.

COMMUNICATION TYPE	DAILY CHOICE EXPERIENCE GROUP					
	Low		Medium		High	
	F		*F*		*F*	
All Communication Types	*F*(3,39)	**6.09** **	*F*(3,39)	**15.59** ***	*F*(3,42)	**104.71** ***
Speech-Real Object	*F*(1,12)	0.20	*F*(1,12)	**4.76** *	*F*(1,14)	**338.69** ***
Speech-Gesture	*F*(1,12)	**5.15** *	*F*(1,12)	**31.64** ***	*F*(1,14)	**84.06** ***
Speech-Signing	*F*(1,12)	**10.38** **	*F*(1,12)	**37.29** ***	*F*(1,14)	**467.47** ***
Real Object-Gesture	*F*(1,12)	**5.79** *	*F*(1,12)	**7.16** *	*F*(1,14)	0.20
Real Object-Signing	*F*(1,12)	**10.32** **	*F*(1,12)	**10.20** **	*F*(1,14)	4.13
Gesture-Signing	*F*(1,12)	2.42	*F*(1,12)	0.97	*F*(1,14)	3.55

*$p<0.05$ **$p<0.01$ ***$p<0.001$

Although there was a significant effect of communication form for each of the daily choice experience groups, for those in the low daily choice experience group there was only a significantly lower rate of

gesture than either speech or real objects (Table 8.15). For the medium group there was also a significantly higher use of speech than real objects, while for the high experience group there was a significantly higher use of speech than any other communication form (Figure 8.7).

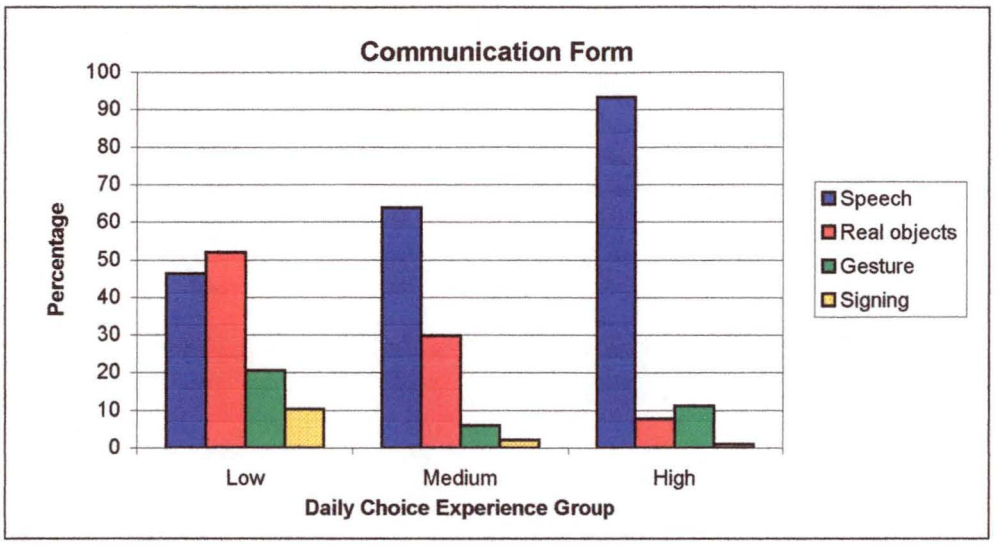

Figure 8.7: Impact of daily choice experience group on the percentage of different *communication forms* to present choice opportunities.

One-way ANOVA showed that there were also significant effects of daily choice experience group on the frequency of speech and real objects to present choice opportunities (Table 8.12). In both cases there was a significant difference between the low and high daily choice experience groups, an increase in the use of speech, and a decrease in the use of real objects, the higher the daily choice experience (Figure 8.7).

Period of Residence

Despite the absence of an effect of period of residence: $F(2,36)=1.13$, $p=0.334$, there was a significant interaction between type of communication form and period of residence: $F(6,108)=8.19$, $p<0.001$. This effect was due to speech being significantly more frequent (Figure 8.8) than the other three communication forms for those in the medium and long period-of-residence groups, but only significantly more frequent than signing for the short period-of-residence group (Table 8.16).

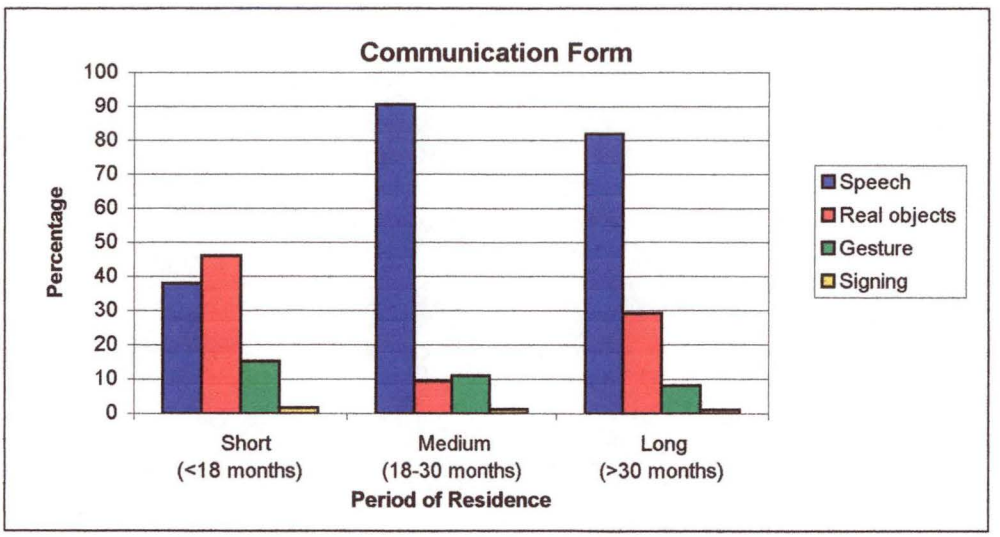

Figure 8.8: *Communication forms* for presenting choice to residents with different periods of residence in their current house.

In addition, the frequency of presentation of choice opportunities using *speech*, was also significantly affected by the time the resident had lived in the current house (Table 8.12). This effect was due to a significantly lower rate of presentations using *speech* for those who had lived in the house for a short time (less than 18 months, 38%) than the two longer periods, medium (18-30 months, 91%), or long time groups (greater than 30 months, 82%).

Table 8.16: Results of one-way ANOVAs comparing the different *forms of communication* for presenting choice opportunities for residents in different period-of-residence groups.

COMMUNICATION FORM	PERIOD OF RESIDENCE GROUP					
	Short		Medium		Long	
	F		*F*		*F*	
All Communication Types	*F*(3,33)	6.12**	*F*(3,33)	63.92***	*F*(3,42)	38.46***
Speech-Real Object	*F*(1,11)	0.26	*F*(1,11)	140.38***	*F*(1,14)	16.78**
Speech-Gesture	*F*(1,11)	4.04	*F*(1,11)	50.90***	*F*(1,14)	125.54***
Speech-Signing	*F*(1,11)	14.57**	*F*(1,11)	14.57**	*F*(1,14)	184.65***
Real Object-Gesture	*F*(1,11)	5.19*	*F*(1,11)	0.03	*F*(1,14)	4.91*
Real Object-Signing	*F*(1,11)	16.53**	*F*(1,11)	3.70	*F*(1,14)	12.00**
Gesture-Signing	*F*(1,11)	4.27	*F*(1,11)	2.60	*F*(1,14)	3.11

*$p<0.05$ **$p<0.01$ ***$p<0.001$

Support Worker

Job Satisfaction

As disability as a covariate was not significant: $F(1,27)=1.70$, $p=0.203$, an ANOVA was used to assess the interaction between communication form to present choices and support worker job satisfaction (Table 8.12).

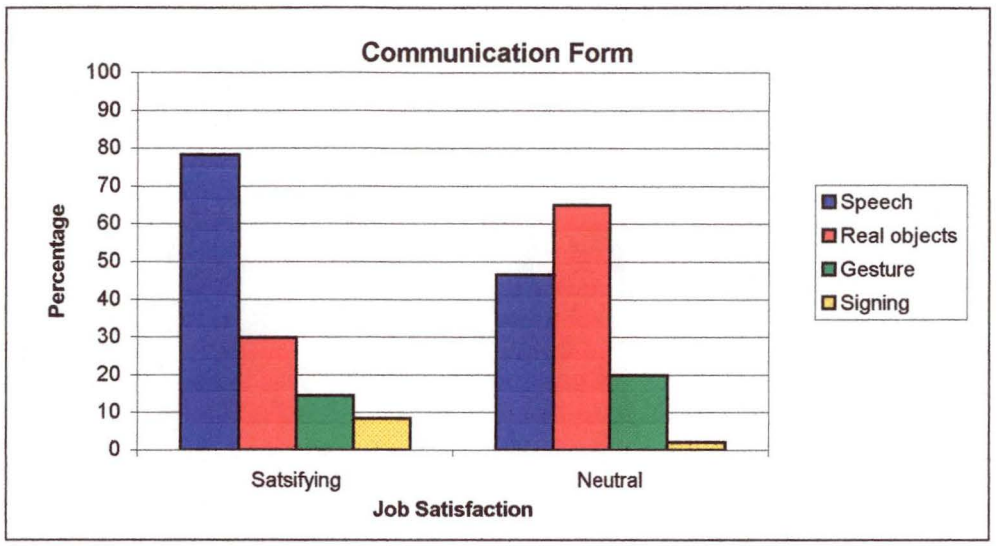

Figure 8.9: *Communication forms* for presenting other-initiated choices as rated by support workers with different levels of rated job satisfaction.

Despite the absence of an effect of job satisfaction: $F(1,32)=0.02$, $p=0.883$, there was a significant interaction between the type of communication form used to present choices and support worker job satisfaction: $F(3,96)=5.28$, $p=0.005$. This effect was due to there being a significant difference between the frequency of communication forms used by those support workers who felt their job was satisfying, but not by those with neutral job satisfaction (Table 8.17). The difference for the satisfied group was due to *speech* being more frequent than all other communication forms (Figure 8.9). There were no significant differences between support worker job satisfaction groups for any individual communication form.

Table 8.17: Results of one-way ANOVAs comparing the different *forms of communication* used to present choices by support workers with different job satisfaction ratings.

COMMUNICATION TYPE	JOB SATISFACTION			
	Satisfied		Neutral	
	F		*F*	
All Communication Types	*F*(3,81)	**38.13** ***	*F*(3,15)	**7.43** *
Speech-Real Object	*F*(1,27)	**25.78** ***	*F*(1,5)	1.45
Speech-Gesture	*F*(1,27)	**114.44** ***	*F*(1,5)	1.64
Speech-Signing	*F*(1,27)	**105.18** ***	*F*(1,5)	**14.31** *
Real Object-Gesture	*F*(1,27)	3.86	*F*(1,5)	**7.87** *
Real Object-Signing	*F*(1,27)	**7.05** *	*F*(1,5)	**79.50** ***
Gesture-Signing	*F*(1,27)	2.25	*F*(1,5)	2.20

*$p<0.05$ **$p<0.01$ ***$p<0.001$

Stage B: EVALUATION AND SELECTION

(3) Limitations on Choice

Support workers indicated whether one or more limitations affected the resident's choice. Overall, fewer choices were affected by some form of limitation (33%) than were not: $F(1,42)=15.95$, $p<0.001$. The two basic types of limitation were: limitations relating to the *residents* themselves (24%), and limitations due to the *environment* (15%). There was no significant difference between the frequencies of these two limitation types: $F(1,42)=4.80$, $p=0.034$.

The possible specific *resident* limitations were: ability (17%), communication skills (7%), experience of options (6%), health factors (5%), and inclination (<1%), while *environmental* limitations consisted of: time (10%), resources (3%), social constraints (2%), finances (1%), and programme involvement (0%). These percentages will not sum to the total for each general limitation category as more than one limitation type could be indicated.

There were significant interactions between the basic types of limitation and the resident period of residence, and the gender of the support worker making the rating. These will be described in the relevant sections below.

Table 8.18 presents a summary of the effects of resident, environment and support worker characteristics on the frequency of different forms of *limitation*.

Table 8.18: Results of one-way ANOVAs on the impact of resident, environmental, and support worker characteristics, on the percentage of *different types of limitation* on choice.

CHARACTERISTICS	LIMITATION TYPE							
	None		Resident				Environment	
					ability	*comm.*		*society*
		F		*F*	*F*	*F*	*F*	*F*
RESIDENT								
Age	*F*(2,40)	0.64	*F*(2,40)	0.47			*F*(2,40)	0.67
Gender	*F*(1,41)	0.10	*F*(1,41)	0.16			*F*(1,41)	0.21
Intellectual Disability	*F*(2,36)	**4.23***	*F*(2,36)	**4.84***			*F*(2,36)	1.63
Physical Disability	*F*(1,40)	3.70	*F*(1,40)	0.92			*F*(1,40)	4.00
Adaptive Functioning	*F*(2,40)	**4.39***	*F*(2,40)	**3.59***	**5.59****		*F*(2,40)	2.64
Communication Skills	*F*(2,32)	0.03	*F*(2,32)	0.06			*F*(2,32)	0.24
Daily Choice Exp.	*F*(2,40)	1.13	*F*(2,40)	0.95			*F*(2,40)	0.45
Major Life Choice	*F*(2,35)	0.52	*F*(2,35)	1.10			*F*(2,35)	2.09
#Period of Residence	*F*(2,36)	0.55	*F*(2,36)	2.41		**6.05****	*F*(2,36)	2.28
Institutionalisation	*F*(2,41)	0.63	*F*(2,41)	0.01			*F*(2,41)	2.65
ENVIRONMENT								
Normalisation	*F*(2,40)	**7.57****	*F*(2,40)	**6.10****	**9.29*****		*F*(2,40)	2.32
Day of week	*F*(1,42)	1.30	*F*(1,42)	0.28			*F*(1,42)	0.25
Time of day	*F*(1,41)	**6.51***	*F*(1,41)	**5.04***			*F*(1,41)	0.76
SUPPORT WORKER								
Age	*F*(2,38)	0.34	*F*(2,38)	0.03			*F*(2,38)	1.67
#Gender	*F*(1,42)	2.11	*F*(1,40)	2.19			*F*(1,41)	0.51 **12.14****
Work in Residence	*F*(2,38)	0.65	*F*(2,38)	1.73			*F*(2,38)	0.43
Hours Worked	*F*(2,34)	0.72	*F*(2,34)	0.60			*F*(2,34)	0.41
Industry Experience	*F*(2,37)	0.98	*F*(2,37)	1.03			*F*(2,37)	0.27
Disability Course	*F*(1,20)	0.54	*F*(1,20)	0.52			*F*(1,20)	3.91
Job Satisfaction	*F*(1,38)	0.11	*F*(1,38)	0.74			*F*(1,38)	1.00
Workshop Attendance	*F*(1,38)	1.22	*F*(1,38)	0.63			*F*(1,38)	**5.50***
Success of Training	*F*(1,33)	1.18	*F*(1,33)	3.09			*F*(1,33)	2.30

Notes: ANOVAs were used for support worker characteristics, as the covariate was not significant,
Highlight - characteristics with significant effects on choice *limitations* to be elaborated in detail,
- characteristics with significant interaction with *limitation type.*
**p*<0.05 ***p*<0.01 ****p*<0.001

Resident

Adaptive Behaviour (SIB)

Although there was no effect of scales of independent behaviour on the frequency of resident limitations, there was a significant effect on the frequency of limitations due to *ability* (Table 8.18). There were however, no significant differences between the frequency of *ability limitations* for any two SIB independence groups: low (30%), medium (11%), and high (8%).

Period of Residence

Despite the absence of an effect of period of residence: $F(2,36)=0.51$, $p=0.606$, there was a significant interaction between type of limitation and period of residence: $F(2,36)=5.76$, $p=0.007$. This effect was due to a significant difference between limitation types for those in the short period-of-residence group: $F(1,11)=15.12$, $p=0.003$. For this group only, there were more *resident* than *environmental* limitations (Figure 8.10). The lack of significant differences between limitation types for the other two period-of-residence groups appears to have been due to a large degree of variation between residents.

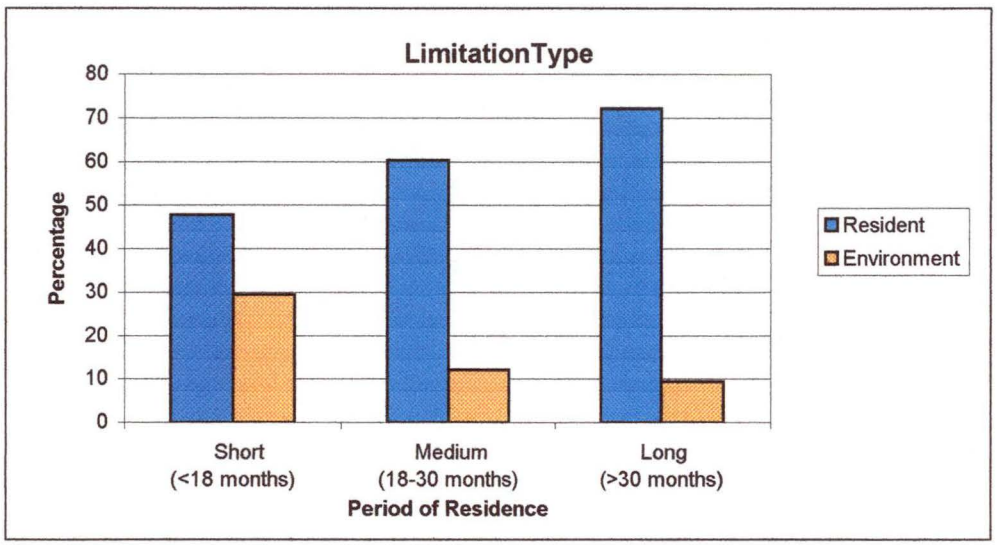

Figure 8.10: *Types of limitation* on choice for residents who had lived for different periods of time in their current residence.

The effect of period of residence on the frequency of limitations due to *communication skills* specifically (Table 8.18) was due to a significant difference between those in the house for a short time (15%) and those in the house for a longer time (2%), but neither was significantly different from the choices of the medium group (8%) that were limited by *communication skills.*

Environment

Normalisation

There was a significant effect of normalisation group on the absence of limitations (Table 8.18), this effect was due to significantly

more limitations for the medium normalisation group than the low normalisation group (Figure 8.11).

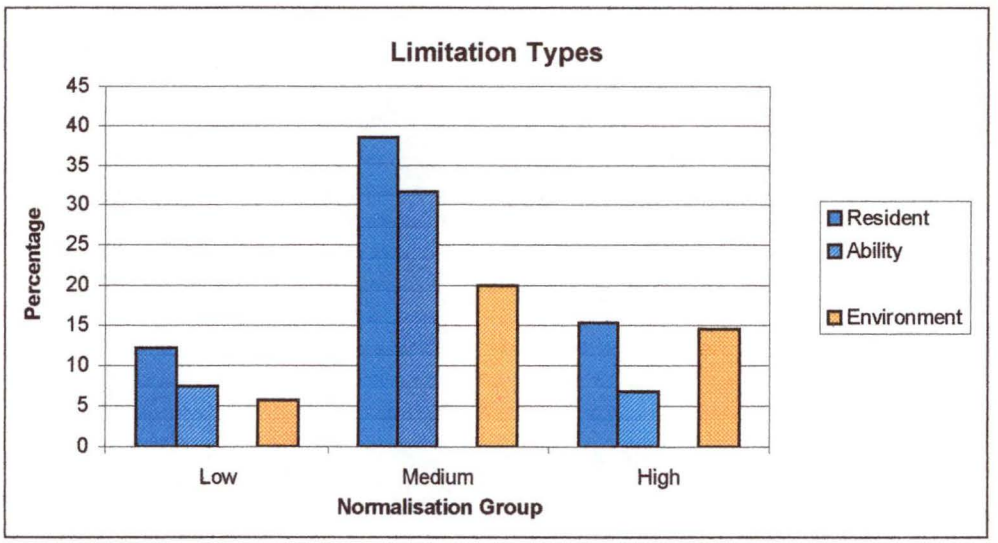

Figure 8.11: Impact of normalisation group on different *types of limitations* on choice.

Although the effect of normalisation group on *resident* limitations did not reach the required level of significance, the effect of normalisation group on limitations as a result of *ability*, did reach significance (Table 8.18). This effect was the result of a significantly higher rate of *ability* limitations for those in the medium normalisation group, than the other two groups.

The difference in limitations between normalisation groups may have been due to different levels of ability of the residents in the different groups. Although there were no differences between normalisation groups on the level of intellectual disability or physical disability, there were significant differences in SIB independence score, the motor skills cluster and the personal living skills cluster. However, only for the SIB independence and SIB motor skills scores, there was a lower mean skill score for the medium than the high normalisation group (Table 8.19).

Table 8.19: Results of one-way ANOVAs on the impact of *normalisation* group on the different measures of *ability*, and mean characteristics scores for each normalisation group.

ABILITY CHARACTERISTIC		F	Normalisation Group Low	Medium	High
Intellectual Disability	*F*(2,36)	0.96			
mean rating			2.1	1.9	1.8
Physical Disability	*F*(2,39)	**4.65***		**H**	**M**
SIB Independence	*F*(2,40)	**6.59****		**H**	**M**
mean score			446	415	462
Motor Skills	*F*(2,40)	**7.74****		**H**	**M**
mean score			425	388	459
Social/Communication Skills	*F*(2,40)	**3.61***		**H**	**M**
mean score			445	423	456
Personal Living Skills	*F*(2,40)	**5.20****		**H**	**M**
mean score			472	442	484
Community Living Skills	*F*(2,40)	**4.10***		**H**	**M**
mean score			441	406	448

Note: Red letter - significantly different from group in column header at 0.01 level (**black** letters, 0.05 level).
***p<0.05 **p<0.01 ***p<0.001**

Support Worker

Gender

As disability as a covariate was not significant: $F(1,35)=3.69$, $p=0.063$, an ANOVA was used to assess the interaction between support worker gender and the type of limitations on choice. Despite the absence of an effect of support worker gender: $F(1,40)=0.21$, $p=0.649$, there was a significant interaction between type of limitation and support worker gender: $F(1,34)=7.70$, $p=0.008$. There was however, no difference between limitation types for males: $F(1,12)=3.12$, $p=0.103$, or females: $F(1,28)=1.95$, $p=0.174$, or between support worker genders for *resident*: $F(1,40)=2.19$, $p=0.147$, or *environmental* limitations: $F(1,40)=0.51$, $p=0.480$.

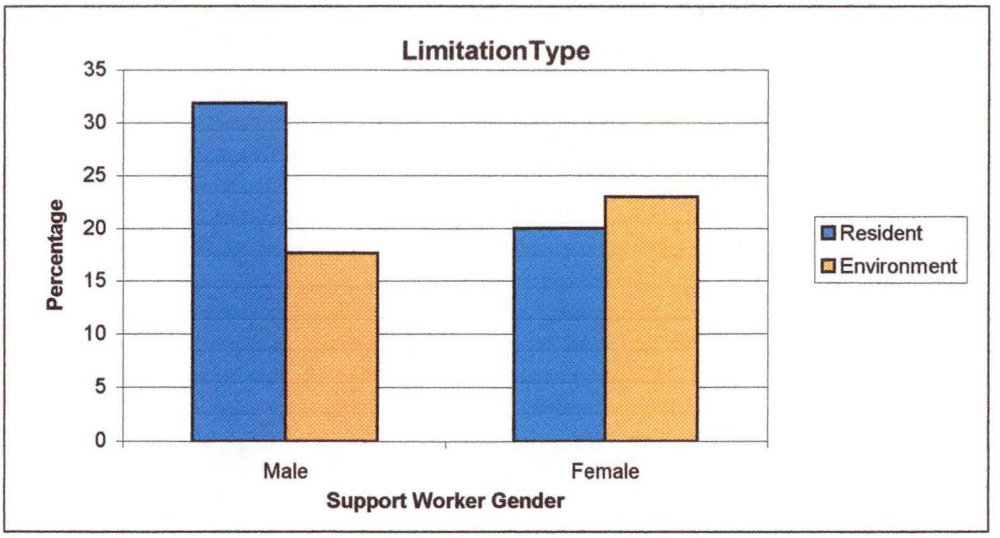

Figure 8.12: *Limitation* types on choice as rated by support workers of different gender.

Although there was no effect of support worker gender on the frequency of resident or environmental limitations generally, there was an effect of support worker gender on the reported frequency of *social limitations* on choice (Table 8.18). Disability level was not significant as a covariate: $F(1,22)=0.20$, $p=0.657$, so an ANOVA was used to determine that there was an effect of support worker gender on social limitations. Figure 8.12 shows that the effect was due to female support workers (1%) rating *social limitations* on choice as less frequent than male support workers (7%).

(4) Responses to Choice

In addition to indicating whether the resident responded emotionally, the support workers also recorded whether the resident communicated a response to the choice opportunity. Significantly more choice opportunities were responded to (77%), than not (33%): $F(1,42)=59.67$, $p<0.001$.

Support workers also indicated one or more means that the resident used to respond to the choice opportunity: *action* (56%), *vocalisation* (24%), *gesture* (7%), and *communication aid* (1%). There was a significant effect of response type: $F(3,126)=58.66$, $p<0.001$, due to significant differences between all response types except between the use of gesture and communication aids to respond to choices (Table 8.20). There were interactions between the means of response and both the presence of a physical disability, and SIB independence group, which are more fully described below.

Table 8.20: Significant differences between the percentages of different *forms of response* to choice opportunities.

RESPONSE TYPE	RESPONSE TYPE			
	Action	**Vocalisation**	**Gesture**	**Aid**
	F(1,42)	*F*(1,42)	*F*(1,42)	*F*(1,42)
None	**23.61*** **	0.05	**11.70** **	**38.05*** **
Action		**25.43*** **	**79.48*** **	**181.65*** **
Vocalisation	**25.43*** **		**19.04*** **	**35.92*** **
Gesture	**79.48*** **	**19.04*** **		**4.94**
Aid	**181.65*** **	**35.92*** **	**4.94***	

**p<0.05 **p<0.01 ***p<0.001*

The results of one-way analyses of variance on the effect of resident characteristics on the frequency of response to any choice opportunity are presented in Table 8.21.

Table 8.21: Results of one-way ANOVAs on the impact of resident and environmental characteristics, and ANCOVAs on support worker characteristics controlling for the intellectual disability of residents, on the percentage of different *means of response* to choice opportunities.

CHARACTERISTICS	MEANS OF RESPONSE								
	None		Action	Vocalisation				Gest.	
		F	*F*	covariate *F*			*F*		*F*
RESIDENT									
Age	*F*(2,40)	0.66	1.11			*F*(2,40)	0.59		1.33
Gender	*F*(1,41)	1.00	0.01			*F*(1,41)	0.58		0.07
Intellectual Disability	*F*(2,36)	2.43	1.65			*F*(2,36)	0.85		0.77
#Physical Disability	*F*(1,40)	0.77	**8.26****			*F*(1,40)	1.31		**10.98****
#Adaptive Functioning	*F*(2,40)	0.73	**4.22***			*F*(2,40)	**3.41***		2.19
Communication Skills	*F*(2,32)	1.55	2.19			*F*(2,32)	2.11		3.02
Daily Choice Exp.	*F*(2,40)	**3.34***	**5.53****			*F*(2,40)	0.18		1.48
Major Life Choice	*F*(2,35)	0.67	0.10			*F*(2,35)	2.87		0.34
Period of Residence	*F*(2,36)	**6.14****	0.43			*F*(2,36)	**3.79***		0.16
Institutionalisation	*F*(2,41)	0.45	0.31			*F*(2,41)	0.47		1.07
ENVIRONMENT									
Normalisation	*F*(2,40)	**4.63***	**4.45***			*F*(2,40)	0.63		0.35
Day of week	*F*(1,42)	**5.74***	1.39			*F*(1,42)	0.15		0.18
Time of day	*F*(1,41)	2.59	**5.82***			*F*(1,41)	**4.55***		2.27
SUPPORT WORKER									
Age	*F*(2,38)	0.17	0.11	*F*(1,33)	**9.27****	*F*(2,33)	0.46		1.16
Gender	*F*(1,42)	2.37	1.49	*F*(1,35)	**8.88****	*F*(1,35)	**4.71***		**4.40***
Work in Residence	*F*(2,38)	0.70	1.34	*F*(1,33)	**8.14****	*F*(2,33)	0.77		1.10
Hours Worked	*F*(2,34)	2.50	1.65	*F*(1,31)	**9.24****	*F*(2,31)	1.16		1.33
Experience time	*F*(2,37)	0.57	1.37	*F*(1,32)	**9.10****	*F*(2,32)	0.79		0.33
Disability Course	*F*(1,20)	1.09	0.23	NS		*F*(1,20)	0.56		4.26
Job Satisfaction	*F*(1,38)	**4.36***	1.41	NS		*F*(1,38)	0.97		0.01
Workshop Attendance	*F*(1,38)	0.27	0.02	*F*(1,33)	**9.44****	*F*(1,33)	0.27		0.94
Success of Training	*F*(1,33)	0.44	3.28	NS		*F*(1,33)	0.18		2.13

Notes: ANOVAs were used for support worker characteristics if the covariate was not significant,
Highlight - characteristics with significant effects on choice *response* to be elaborated in detail,
- characteristics with significant interaction with *means of response*.
NS-non significant
***p<0.05 **p<0.01 ***p<0.001**

Resident

Physical Disability

There was a significant interaction between the means of response to choice opportunities and the presence of a physical disability: $F(3,120)=7.22$, $p=0.002$, but no effect of physical disability: $F(1,40)=0.07$, $p=0.793$.

Table 8.22: Results of one-way ANOVAs comparing the percentage of different *means of response* to choice opportunities for residents with and without a physical disability.

RESPONSE TYPES	Physical Disability			
	No		Yes	
		F		*F*
All Response Types	*F*(3,78)	**83.45*** **	*F*(3,42)	**8.14** **
Action-Vocalisation	*F*(1,26)	**36.61*** **	*F*(1,14)	0.96
Action-Gesture	*F*(1,26)	**215.20*** **	*F*(1,14)	4.41
Action-Aid	*F*(1,26)	**208.94*** **	*F*(1,14)	**34.57*** **
Vocalisation-Gesture	*F*(1,26)	**19.84*** **	*F*(1,14)	2.53
Vocalisation-Aid	*F*(1,26)	**22.20*** **	*F*(1,14)	**17.75** **
Gesture-Aid	*F*(1,26)	**5.66***	*F*(1,14)	**6.73***

**p*<0.05 ***p*<0.01 ****p*<0.001

The interaction appears to have been the result of significant differences between all means of response for those without a physical disability except gesture and communication aid, but only significantly lower response rates using communication aid than action or vocalisation for those with a physical disability (Table 8.22).

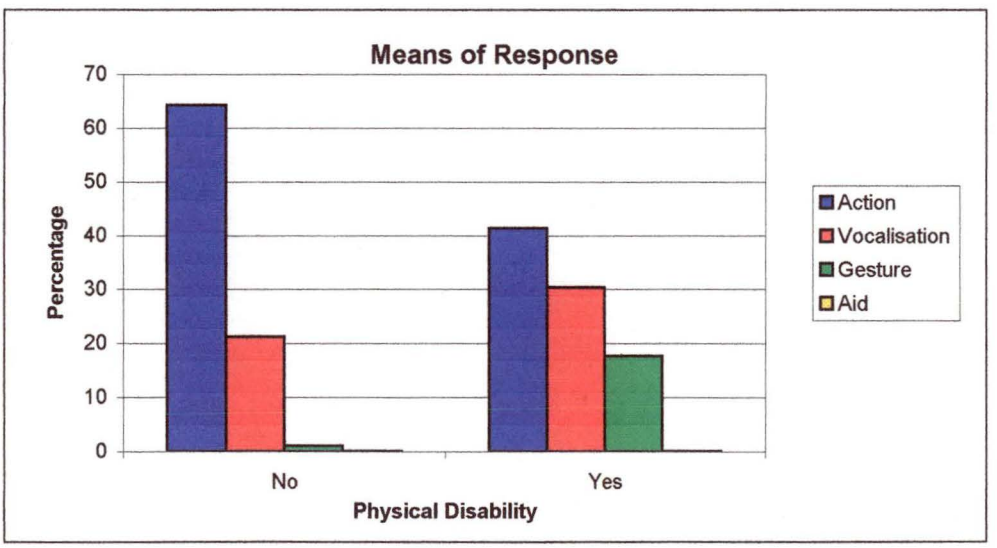

Figure 8.13: *Means of response* to choice opportunities for residents with and without a physical disability.

One-way ANOVA showed that there were also significantly more choices being responded to using action (Table 8.21), and significantly fewer choices responded to using gesture, for those without a physical disability (Figure 8.13).

Adaptive Behaviour (SIB)

There was also a significant interaction between the means of responses and SIB independence group: $F(6,120)=4.25$, $p=0.003$, but no effect of SIB independence group: $F(2,40)=0.42$, $p=0.662$. Although there were no differences between SIB independence groups for the frequency of any means of response, there were different patterns of response for each SIB group (Table 8.23).

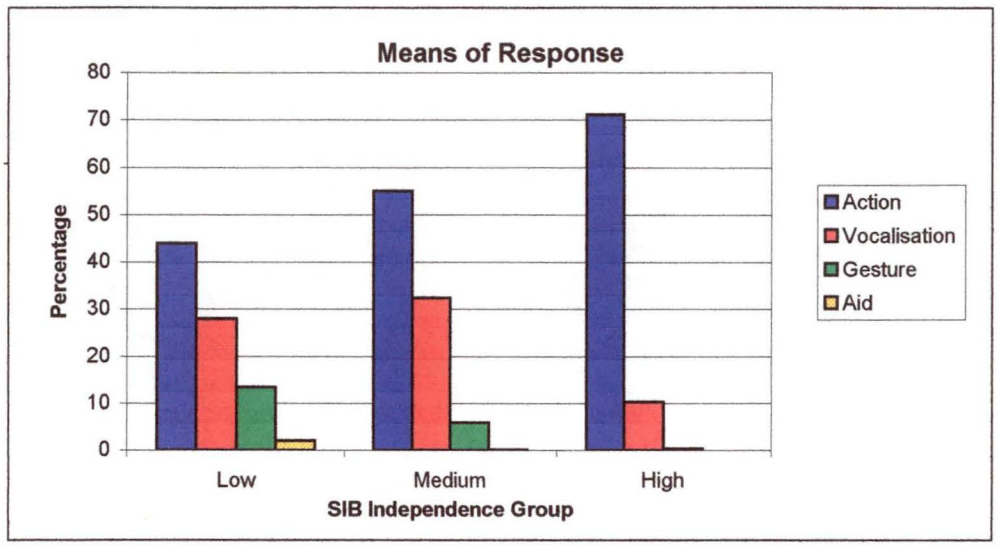

Figure 8.14: *Means of response* to choice opportunities for residents in different SIB independence groups.

Table 8.23: Results of one-way ANOVAs on the impact of SIB independence group on the percentage of different *means of response* to choice opportunities.

RESPONSE TYPES	SIB Independence Group					
	Low		Medium		High	
	F		*F*		*F*	
All Response Types	*F*(3,42)	**8.37** **	*F*(3,42)	**26.53** ***	*F*(3,36)	**81.02** ***
Action-Vocalisation	*F*(1,14)	1.76	*F*(1,14)	**6.34** *	*F*(1,12)	**66.37** ***
Action-Gesture	*F*(1,14)	**8.13** *	*F*(1,14)	**40.23** ***	*F*(1,12)	**110.96** ***
Action-Aid	*F*(1,14)	**32.42** ***	*F*(1,14)	**103.91** ***	*F*(1,12)	**113.37** ***
Vocalisation-Gesture	*F*(1,14)	3.84	*F*(1,14)	**11.55** **	*F*(1,12)	**7.61** *
Vocalisation-Aid	*F*(1,14)	**9.90** **	*F*(1,14)	**28.79** ***	*F*(1,12)	**7.59** *
Gesture-Aid	*F*(1,14)	3.60	*F*(1,14)	1.36	*F*(1,12)	2.18

*$p<0.05$ **$p<0.01$ ***$p<0.001$

For the low SIB independence group the use of communication aids was significantly lower than action or vocalisation. For the medium group there were significant differences between all means of response

except between action and vocalisation, and between gesture and aid. The high SIB group however, had significantly higher rates of action responses than any other response type (Figure 8.14).

Daily Choice Experience

There was a significant difference between the low and high daily choice experience groups for the frequency of action responses to choice opportunities (Table 8.21). There were more action responses when the resident had more choice experience (Figure 8.15).

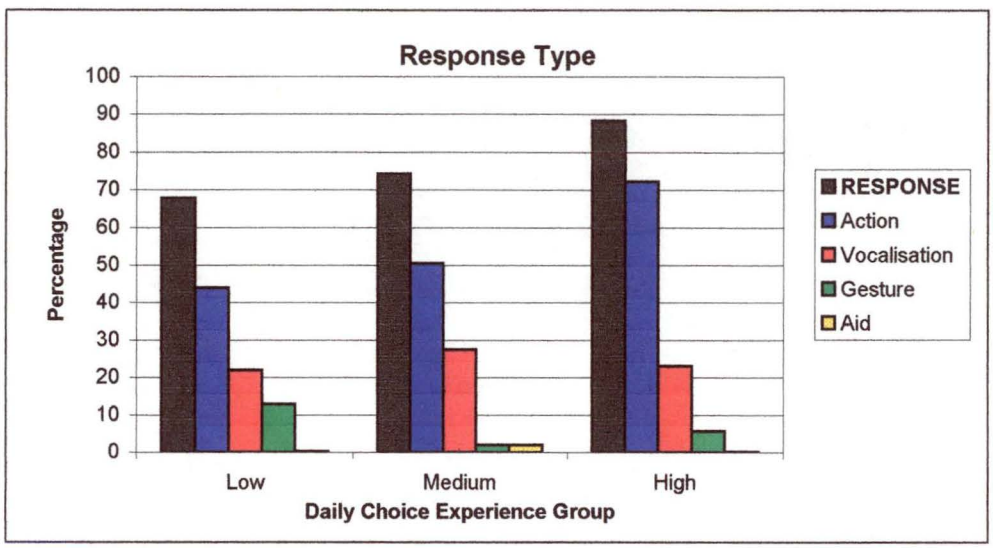

Figure 8.15: Impact of daily choice experience on the percentage of different *types of response* to choice opportunities.

Period of Residence

There was a significant effect of period of residence on the overall response rate to choice opportunities (Table 8.21). This effect was due to a significant difference between the responses rates of those in the house for a short time (<18 months, 62%) and those in the house for a medium time (18-30 months, 91%), but no difference between these groups and those living in the house for a long period (>31 months, 78%).

Stage C: ACTING ON THE SELECTION

(5) Follow-Through of Choice

Significantly more choice responses were followed through (96%), than not: $F(1,37)=2961.34$, $p<0.001$. Support workers also indicated who followed through with the choice, the *resident alone* (63%), the *resident and another* together (17%), or the *support worker or another* alone (16%).

There was a effect of agent-of-follow-through: $F(2,84)=42.09$, $p<0.001$, and there were significant differences between all *agents-of-follow-through* possibilities except between *other* and *resident and other combined* (see Table 8.24).

Table 8.24: Significant differences between the percentage of different *agents-of-follow-through* for choice.

FOLLOW THROUGH AGENT	FOLLOW-THROUGH AGENT		
	Resident only	Resident & Other	Other only
	$F(1,42)$	$F(1,42)$	$F(1,42)$
None	209.32***	23.14***	10.59**
Resident only		64.16***	40.00***
Resident & Other	64.16***		0.05
Other only	40.00***	0.05	

*$p<0.05$ **$p<0.01$ ***$p<0.001$

There were also significant interactions between agent-of-follow-through and each of SIB group, daily choice experience group, major life choice score, and normalisation group. These are described in the relevant section below.

The results of one-way analyses of variance tests on the effect of characteristics on the frequency of choice opportunities followed through with are presented in Table 8.25.

Table 8.25: Results of one-way ANOVAs on the impact of resident and environmental characteristics, and ANCOVAs on support worker characteristics controlling for the intellectual disability of residents, on the percentage of various *types of follow-through* of choice opportunities.

CHARACTERISTICS	FOLLOW-THROUGH AGENT							
	None		Resident only		Other only		Res. & Other	
	F		covar. *F*		*F*		covar. *F*	*F*
RESIDENT								
Age	*F*(2,40)	0.60		*F*(2,40)	3.01		*F*(2,40)	0.95	**4.19***
Gender	*F*(1,41)	0.00		*F*(1,41)	0.02		*F*(1,41)	0.04	0.00
Intellectual Disability	*F*(2,36)	1.06		*F*(2,36)	**7.62****		*F*(2,36)	**6.48****	1.76
Physical Disability	*F*(1,40)	0.40		*F*(1,40)	3.50		*F*(1,40)	3.04	0.25
#Adaptive Functioning	*F*(2,40)	0.79		*F*(2,40)	**15.31*****		*F*(2,40)	**13.07*****	2.60
Communication Skills	*F*(2,32)	1.48		*F*(2,32)	1.47		*F*(2,32)	2.85	0.17
#Daily Choice Exp.	*F*(2,40)	**4.08***		*F*(2,40)	**5.90****		*F*(2,40)	**6.49****	0.18
#Major Life Choice	*F*(2,35)	1.14		*F*(2,35)	**5.77****		*F*(2,35)	**4.33***	**3.54***
Period of Residence	*F*(2,36)	0.41		*F*(2,36)	2.92		*F*(2,36)	**3.37***	2.03
Institutionalisation	*F*(2,41)	0.33		*F*(2,41)	0.53		*F*(2,41)	0.81	0.06
ENVIRONMENT								
#Normalisation	*F*(2,40)	**6.93****		*F*(2,40)	**4.71***		*F*(2,40)	**6.45****	0.95
Day of week	*F*(1,42)	2.21		*F*(1,42)	0.10		*F*(1,42)	**4.27***	0.91
Time of day	*F*(1,41)	2.58		*F*(1,41)	3.77		*F*(1,41)	0.01	1.16
SUPPORT WORKER								
Age	*F*(2,38)	0.18	**11.43****	*F*(2,33)	0.31	**8.39****	*F*(2,33)	0.25	0.54
Gender	*F*(1,42)	**4.88***	**11.17****	*F*(1,35)	0.92	**7.73****	*F*(1,35)	0.08	0.50
Work in Residence	*F*(2,38)	0.25	**7.64****	*F*(2,33)	0.44	NS	*F*(2,38)	1.82	0.07
Hours Worked	*F*(2,34)	0.67	**12.59****	*F*(2,31)	0.81	**9.96****	*F*(2,31)	3.15	0.81
Experience time	*F*(2,37)	1.76	**12.24****	*F*(2,32)	0.92	**8.11****	*F*(2,32)	1.10	1.96
Disability Course	*F*(1,20)	0.98	**9.50****	*F*(1,17)	0.04	NS	*F*(1,20)	2.49	1.10
Job Satisfaction	*F*(1,38)	0.53	**11.15****	*F*(1,33)	0.03	**10.58****	*F*(1,33)	2.42	**6.22***
Workshop Attendance	*F*(1,38)	0.27	**10.21****	*F*(1,33)	0.30	**7.95****	*F*(1,33)	0.22	3.89
Success of Training	*F*(1,33)	1.19	**11.25****	*F*(1,29)	0.04	**7.84****	*F*(1,29)	1.98	2.05

Notes: ANOVAs were used for support worker characteristics if the covariate was not significant,
Highlight - characteristics with significant effects on choice *follow-through* to be elaborated in detail,
- characteristics with significant interaction with *follow-through* agent
NS-non significant
***p*<0.05 ****p*<0.01 *****p*<0.001

Resident

Intellectual Disability

There was an effect of intellectual disability level, on the frequency of both *resident only* follow-through, and follow-through by *others only* (Table 8.25). Tukey tests showed that residents with a severe intellectual disability followed through with fewer choices themselves, and more choices were *followed through by others* than those with the two milder levels of intellectual disability (Figure 8.16).

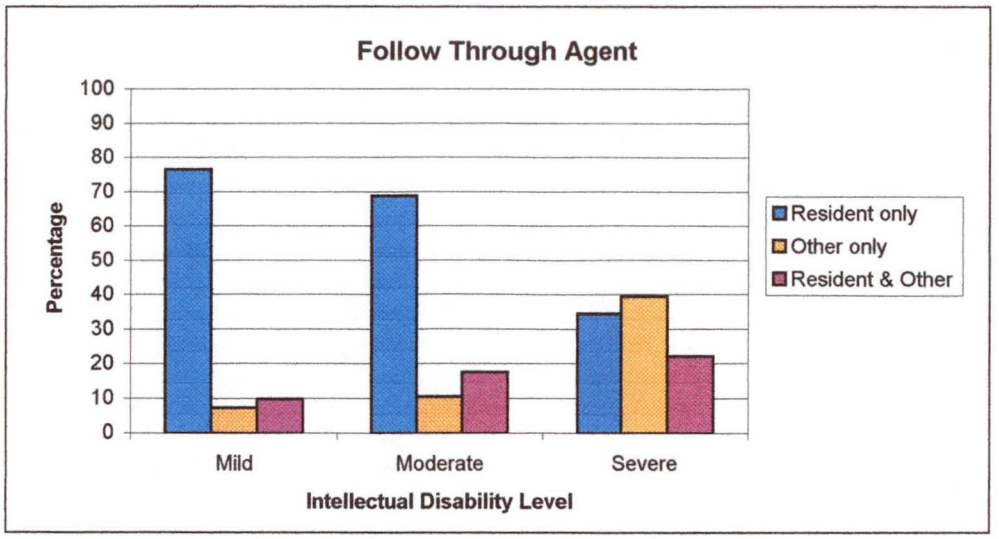

Figure 8.16: Impact of intellectual disability level on the percentage of choice opportunities *followed-through* by different agents.

Adaptive Behaviour (SIB)

There was a significant interaction between the agent-of-follow-through and SIB independence group: $F(4,80)=12.08$, $p<0.001$, but no effect of SIB independence group: $F(2,40)=0.79$, $p=0.463$. There were no differences between the frequencies of different agents-of-follow-through for those in the low SIB group, but significantly more follow-through by residents alone than follow-through by others either alone or with the resident in the other two groups (Table 8.26).

Table 8.26: Results of one-way ANOVAs on the impact of SIB independence group on the percentage of different *agent-of-follow-through* of choice response.

FOLLOW THROUGH	SIB Independence Group					
	Low		Medium		High	
	F		*F*		*F*	
Agent-of-Follow-Through	$F(2,28)$	1.46	$F(2,28)$	**38.96** ***	$F(2,24)$	**135.03** ***
Resident-Other	$F(1,14)$	0.09	$F(1,14)$	**51.08** ***	$F(1,14)$	**215.59** ***
Resident-Resident & Other	$F(1,14)$	3.39	$F(1,14)$	**42.30** ***	$F(1,14)$	**122.54** ***
Other-Resident & Other	$F(1,14)$	2.57	$F(1,14)$	2.72	$F(1,14)$	3.05

*$p<0.05$ **$p<0.01$ ***$p<0.001$

One-way ANOVA showed that there were also significant effects of SIB independence group on frequency of *resident follow-through* and the frequency of *others following through* with choices (Table 8.25). There was a significantly lower rate of *resident only follow-through,* and a

significantly higher rate of *others following through* with choices, by those in the low SIB group than the other two groups (Figure 8.17).

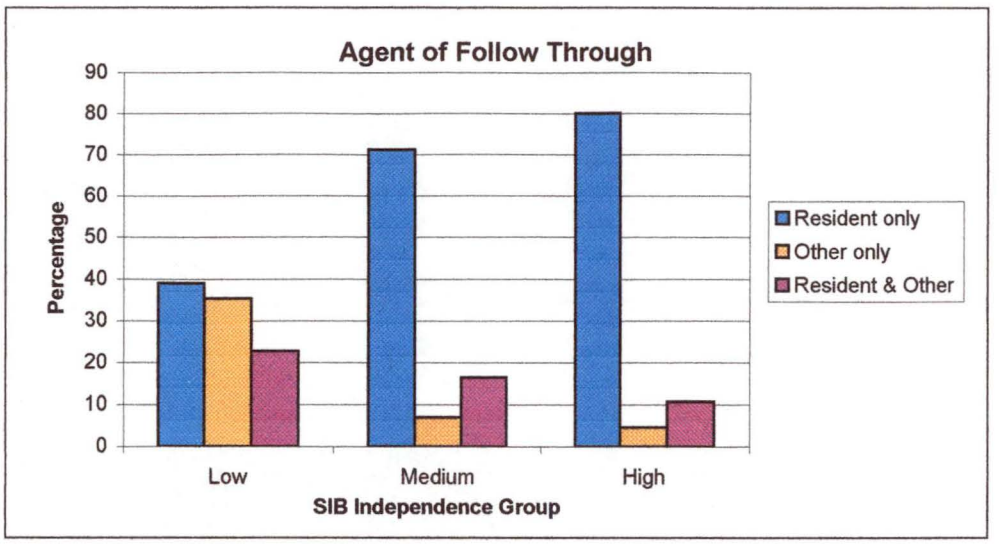

Figure 8.17: Percentage of different *agents-of-follow-through* of choice response for residents in different SIB independence groups.

When the different SIB clusters were analysed for their impact on follow-through of choice opportunities by the *resident only* or *others only*, the results in Table 8.27 were found.

Table 8.27: One-way ANOVA on the effect of adaptive functioning (SIB) groups on the percentage of different choice *follow-through agents*.

SIB CLUSTER	FOLLOW-THROUGH AGENT							
	Resident only				Other only			
	SIB GROUP				SIB GROUP			
	F(2,40)	Low	Med.	High	*F*(2,40)	Low	Med.	High
INDEPENDENCE	15.31***	M H	L	L	13.07***	H M	L	L
Motor Skills	12.78***	M H	L	L	13.44***	H M	L	L
Social Interaction / Comm. Skills	8.80**	M H	L	L	8.44***	H M	L	L
Personal Living Skills	33.51***	M H	L	L	29.03***	H M	L	L
Community Living Skills	8.07**	M H	L	L	11.35***	H M	L	L

Note: Red letter - significantly different from group in column header at 0.01 level (**black** letters, 0.05 level).
*$p<0.05$ **$p<0.01$ ***$p<0.001$

This shows that follow-through by either the *resident only* and *others only* were significantly influenced by most of the skills measured by the SIB clusters. The more developed the skills, the more likely the resident was to follow-through with the choice response and the less likely

that others would follow-through with the choice alone (Figure 8.18). Although all of these skills may not be directly involved in carrying through with the choice, they may contribute to a sense of confidence and independence, or they may just correlate with the skills that are required.

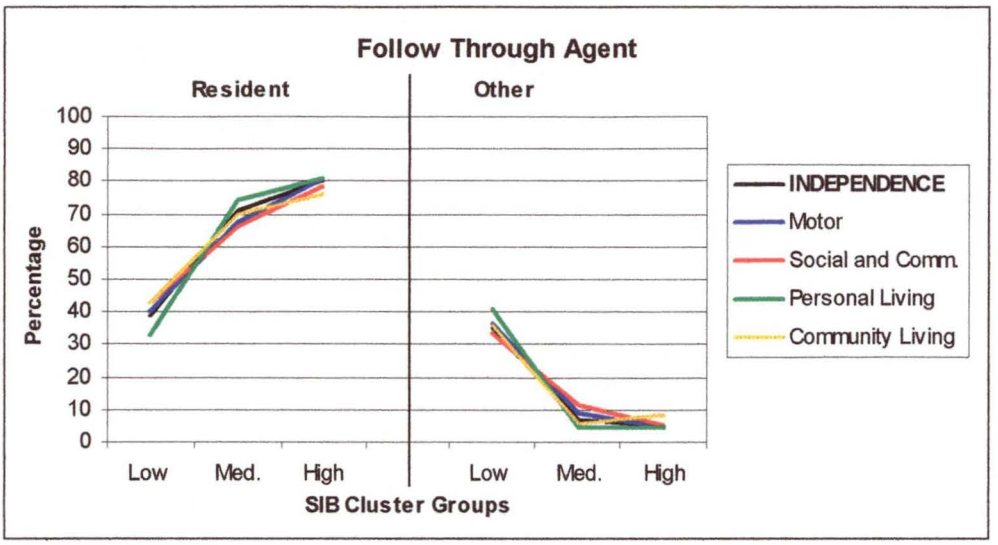

Figure 8.18: Impact of SIB independence subscale groups on the percentage of *follow-through* by residents only and others only.

Daily Choice Experience

There was an interaction between agent-of-follow-through and daily choice experience group: $F(4,80)=5.08$, $p=0.004$, but no effect of daily choice experience group: $F(2,40)=4.08$, $p=0.024$.

Table 8.28: Results of one-way ANOVAs on the impact of daily choice experience group on the percentage of different *agent-of-follow-through* of choice response.

FOLLOW THROUGH AGENT	DAILY CHOICE EXPERIENCE GROUP					
	Low		Medium		High	
	F		*F*		*F*	
Agent-of-Follow-Through	*F*(2,26)	2.73	*F*(2,26)	**16.20*** **	*F*(2,28)	**111.22*** **
Resident-Other	*F*(1,13)	0.99	*F*(1,13)	**17.27** **	*F*(1,14)	**219.41*** **
Resident-Resident & Other	*F*(1,13)	**6.11***	*F*(1,13)	**21.82*** **	*F*(1,14)	**83.74*** **
Other-Resident & Other	*F*(1,13)	2.52	*F*(1,13)	0.15	*F*(1,14)	**9.52** **

***$p<0.05$ **$p<0.01$ ***$p<0.001$**

There was a significant difference between the frequency for different *follow-through agents* for the medium and high daily experience groups only (Table 8.28). For the medium group the resident was more

likely to follow-through with the choice alone, than for support workers to follow-through with the choice either alone, or with the resident. For the high daily choice experience group, there were significant differences between each pair of follow-through agents, *resident alone* was most likely, then *resident and support worker together*, and *support worker alone* was least likely.

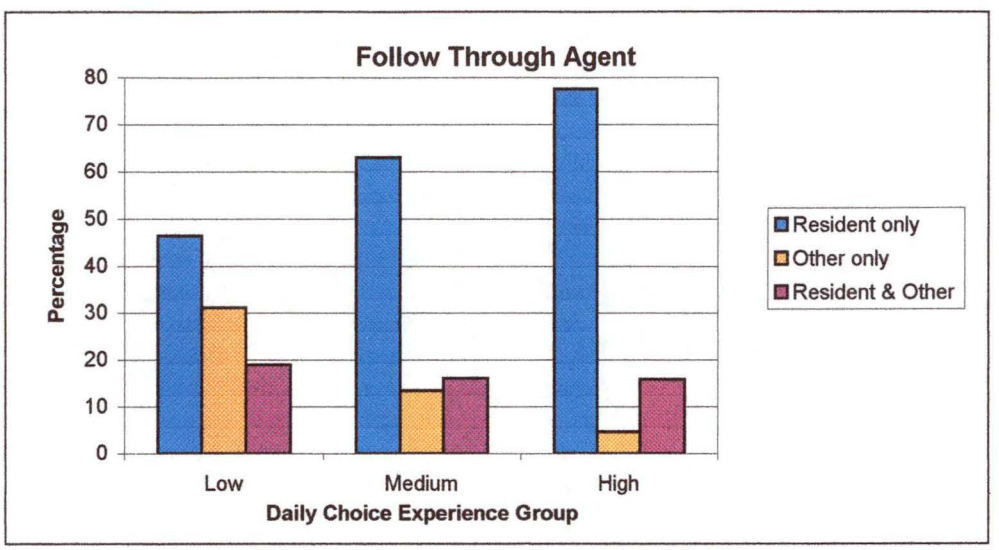

Figure 8.19: Impact of daily choice experience on the percentage of choices *followed-through* by different agents.

One-way ANOVA showed that there was a significant effect of daily choice experience group on the frequency of follow-through by both *residents only* and *others only* (Table 8.25). In both cases Tukey tests indicated that there was a significant difference between the low and high daily choice experience groups, *residents* were more likely to follow-through with choices, and *others* less likely to follow-through with choices the more experience the resident had in making daily choices (Figure 8.19).

Major Life Choice Experience

A significant interaction between the agent-of-follow-through and major life choice experience group: $F(4,70)=4.93$, $p=0.005$, was found, but no effect of SIB independence group: $F(2,35)=1.14$, $p=0.333$ (Figure 8.21). There were no differences between the frequencies of different agents-of-follow-through for those in the low major life choice experience group, but significantly more follow-through by *residents* alone than follow-through by *others* either *alone* or with the *resident* in the two groups more experienced in major life choice-making (Table 8.29).

Table 8.29: Results of one-way ANOVAs on the impact of major life choice experience group on the percentage of different *agent-of-follow-through* of choice response.

FOLLOW THROUGH AGENT	Major Life Choice Experience Group					
	Low		Medium		High	
	F		*F*		*F*	
Agent-of-Follow-Through	$F(2,22)$	2.07	$F(2,24)$	**22.33** ***	$F(2,24)$	**70.39** ***
Resident-Other	$F(1,11)$	0.92	$F(1,12)$	**33.59** ***	$F(1,12)$	**62.42** ***
Resident-Resident & Other	$F(1,11)$	**5.06** *	$F(1,12)$	**21.48** **	$F(1,12)$	**129.51** ***
Other-Resident & Other	$F(1,11)$	1.21	$F(1,12)$	3.24	$F(1,12)$	0.00

*$p<0.05$ **$p<0.01$ ***$p<0.001$

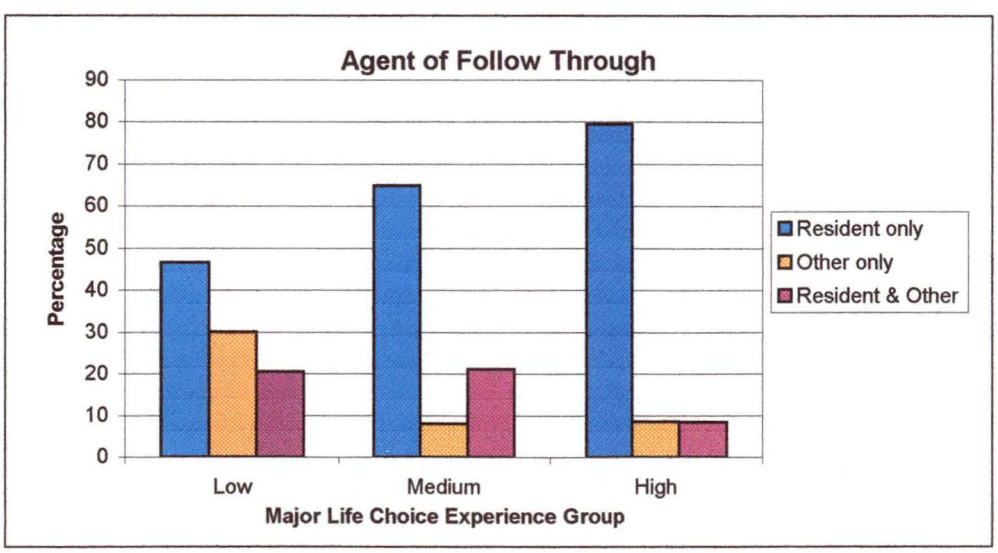

Figure 8.20: Percentage of different *agents-of-follow-through* for choice responses of residents in different major life choice experience groups.

One-way ANOVA showed that there was also a significant effect of major life choice experience group on the frequency of *resident follow-through* (Table 8.25), Tukey tests indicated there was a significantly higher rate of *resident follow-through* for those in the high major life choice experience group than the low group (Figure 8.20).

Environment

Normalisation

There was a significant interaction between the agent-of-follow-through and the normalisation group: $F(2,80)=4.63$, $p=0.006$, and an effect of normalisation group: $F(2,40)=6.93$, $p=0.003$ (Figure 8.21). The interaction was due to the lack of difference between frequencies of agents-of-follow-through for the medium normalisation group, while for the low and high normalisation groups, *residents* were most likely to follow-through with the choices alone (Table 8.30).

Table 8.30: Results of one-way ANOVAs on the impact of normalisation group on the percentage of different *agent-of-follow-through* of choice responses.

FOLLOW THROUGH AGENT	Normalisation Group					
	Low		Medium		High	
	F		*F*		*F*	
Agent-of-Follow-Through	$F(2,28)$	**48.60** ***	$F(2,32)$	3.57	$F(2,30)$	**50.98** ***
Resident-Other	$F(1,9)$	**79.76** ***	$F(1,16)$	1.56	$F(1,15)$	**86.06** ***
Resident-Resident & Other	$F(1,9)$	**36.95** ***	$F(1,16)$	**8.07** *	$F(1,15)$	**53.25** ***
Other-Resident & Other	$F(1,9)$	1.98	$F(1,16)$	2.69	$F(1,15)$	3.08

*$p<0.05$ **$p<0.01$ ***$p<0.001$

There were significant effects of normalisation group on the frequency of *follow-through* of choice responses generally and of follow-through by others particularly were indicated by one-way ANOVA and shown in Table 8.24. Tukey tests showed that the first was due to a significantly lower rate of *follow-through* for those in the low normalisation group than either the medium or high normalisation groups (Figure 8.21). Despite the significant effect of normalisation on *others following through* choices (Table 8.25), there were no significant differences between individual normalisation groups.

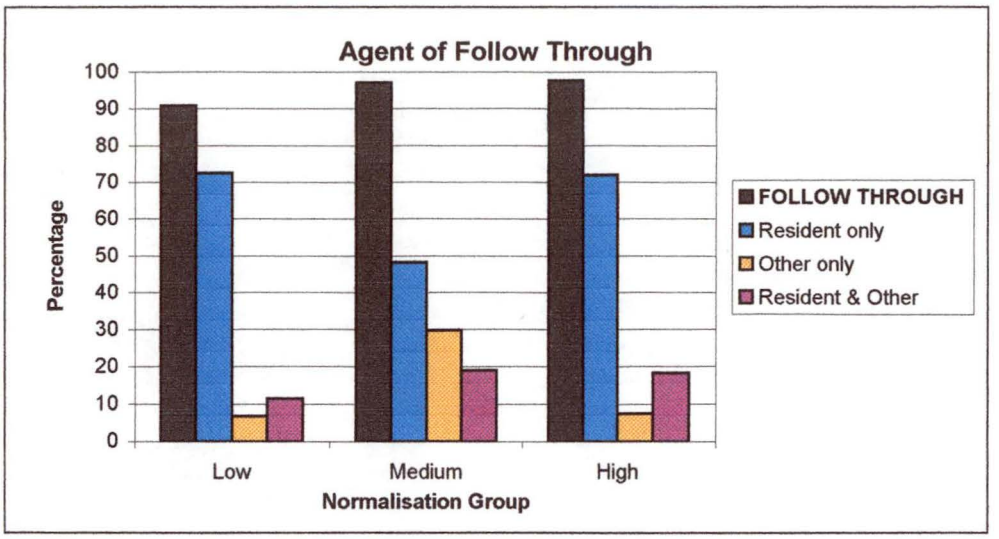

Figure 8.21: Percentage of different *agents-of-follow-through* of choices for residents in different normalisation groups.

(6) Impact of Choice

Support workers indicated whether there was an *impact* (32%) of the choice on either or both the *resident* themselves (29%) or *others* (11%). Significantly more choices had no impact than did: $F(1,42)=15.96$, $p<0.001$, but when there was an impact it was significantly more likely to be on the *resident*: $F(1,42)=23.26$, $p<0.001$, than on *others*.

There were also interactions between who the impact was on, and the period of time the resident had lived in the house, and the time of day the choice was made. These effects are described below.

Support workers also indicated the specific type(s) of impact of the choice opportunity or response. The resident impact types were: *increasing independence* (18%), *changing resident routine* (11%), and *new experience* (1%). The types of impact on others were: *less work for support workers* (7%), *extra work for support workers* (3%), and *interfered with the choices of others* (1%). These percentages will not sum to the total for each general impact category as more than one impact type could be indicated.

The results of one-way analyses of variance tests on the effect of characteristics on the frequency of impact of choice are presented in Table 8.31.

Table 8.31: Results of one-way ANOVAs on the impact of resident, environment and support worker characteristics, on the percentage of different *types of impact* of choice opportunities.

CHARACTERISTICS	IMPACTS								
	None	Resident				Other		
			change routine	*new exp.*	*indep.*		*extra work*	*less work*
	F	*F*	*F*	*F*	*F*	*F*	*F*	*F*
RESIDENT								
Age	*F*(2,40) 0.04	*F*(2,40) 0.06				*F*(2,40) 0.84		
Gender	*F*(1,41) 0.05	*F*(1,41) 0.01				*F*(1,41) 1.59		
Intellectual Disability	*F*(2,36) 0.29	*F*(2,36) 0.13				*F*(2,36) 2.87		
Physical Disability	*F*(1,40) 0.85	*F*(1,40) 0.79				*F*(1,40) 0.27		
Adaptive Functioning	*F*(2,40) 0.15	*F*(2,40) 0.40				*F*(2,40) 1.25		
Communication Skills	*F*(2,32) 1.90	*F*(2,32) 1.27				*F*(2,32) 3.20		
Daily Choice Exp.	*F*(2,40) 0.04	*F*(2,40) 0.10				*F*(2,40) 1.68		
Major Life Choice	*F*(2,35) 2.81	*F*(2,35) 3.14				*F*(2,35) 2.30		
#Period of Residence	*F*(2,36) **3.60***	*F*(2,36) **5.82****	**9.17*****			*F*(2,36) 1.05		
Institutionalisation	*F*(2,41) **5.63***	*F*(2,41) 1.76				*F*(2,41) **30.43*****	**8.55****	**21.05*****
ENVIRONMENT								
Normalisation	*F*(2,40) 0.27	*F*(2,40) 0.12				*F*(2,40) 2.12		
Day of week	*F*(1,42) 3.36	*F*(1,42) 2.54				*F*(1,42) 0.40		
#Time of day	*F*(1,41) **9.04****	*F*(1,41) **5.64***				*F*(1,41) 0.27		
SUPPORT WORKER								
Age	*F*(2,38) 0.20	*F*(2,38) 0.18				*F*(2,38) 0.29		
Gender	*F*(1,42) 1.68	*F*(1,40) 1.05				*F*(1,40) 2.55		
Work in Residence	*F*(2,38) 1.86	*F*(2,38) 1.78				*F*(2,38) 0.33		
Hours Worked	*F*(2,34) 0.37	*F*(2,34) 0.53				*F*(2,34) 0.26		
Industry Experience	*F*(2,37) 1.91	*F*(2,37) 1.79	**5.44****			*F*(2,37) 0.59		
Disability Course	*F*(1,20) 0.75	*F*(1,20) 0.64				*F*(1,20) 1.22		
Job Satisfaction	*F*(1,38) 0.29	*F*(1,38) 0.10				*F*(1,38) 0.04		
Workshop Attendance	*F*(1,38) 1.11	*F*(1,38) 1.21				*F*(1,38) 1.58		
Success of Training	*F*(1,33) **26.61*****	*F*(1,33) **24.22*****		**8.86****	**23.58*****	*F*(1,33) **10.60****		**12.21****

Notes: ANOVAs were used for support worker characteristics, as the covariate was not significant,
Highlight - characteristics with significant effects on choice *impact* to be elaborated in detail,
- characteristics with significant interaction with *impact type*.
***p<0.05 **p<0.01 ***p<0.001**

Resident

Period of Residence

Despite the absence of an effect of period of residence: $F(2,36)=2.26$, $p=0.119$, there was a significant interaction between type of impact of choice and period of residence: $F(2,36)=8.95$, $p=0.001$. This effect was due to a significantly higher rate of *resident* impact than impact on *others* for the short period-of-residence group only: $F(1,11)=39.98$, $p<0.001$.

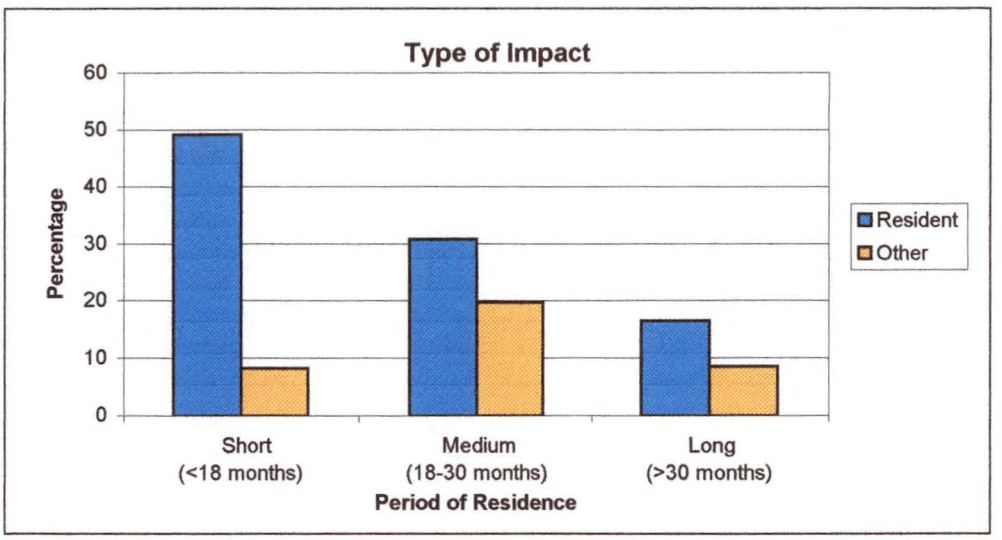

Figure 8.22: Types of *impact of choice* for residents who had lived for different periods of time in their current residence.

One-way ANOVA indicated that there was also a significant effect of the period-of-residence group on the proportion of choices that had an *impact on the resident* (Table 8.31). Tukey tests showed that there were significantly more *resident* impacts for those in the short stay, than the long stay group (Figure 8.22). The specific type of resident impact that appears to be relevant was *change in resident's routine.* This effect was due to a significantly lower rate of *changing routine* for those in the house for a long time (4%), than a short time (25%), but there was no difference between either of these and the medium time in house group (10%).

Institutionalisation

The significant effect of institutionalisation on frequency of *impact on others* indicated in Table 8.31 was due to the *impact on others* being considerably higher when the resident had never lived in an institution (Figure 8.23). There was also a significant effect of institutionalisation on the frequency of the impacts - *less work for support workers,* and *extra work for support workers* due to a greater impact of both following the choices of those who had not been institutionalised.

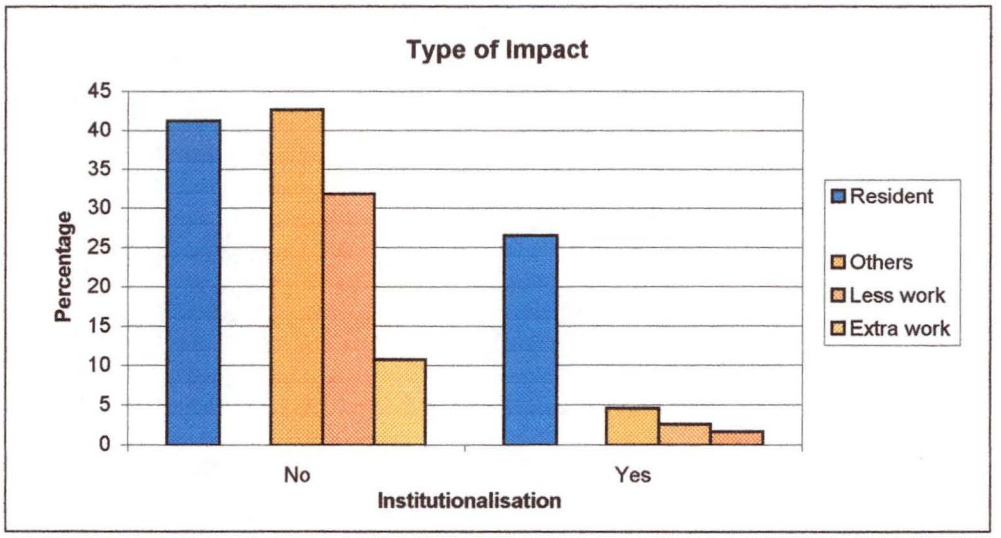

Figure 8.23: Effect of resident institutionalisation on different types of *impact of choice.*

Environment

Time of Day

Despite the lack of effect of time of day on either type of impact individually (Table 8.31), there was an interaction between type of impact and time of day: $F(1,41)=11.77$, $p=0.001$.

This was due to significantly more *resident* impacts than impacts on *others* in both the morning (24% and 11% respectively): $F(1,41)=20.75$, $p<0.001$, and the afternoon (36% and 10% respectively): $F(1,41)=42.54$, $p<0.001$, but no difference between impacts on *residents* and *others* in the morning than the afternoon.

The effect of time of day indicated by one-way ANOVA on impacts generally (Table 8.31) appears to be the result of a significantly higher rate of impact in the afternoon (39%) than the morning (26%).

Support Worker

Industry Experience

Although there was no effect of support worker industry experience on the frequency of resident impacts of choice, there was an effect on *changing resident's routine* (Table 8.31). This was due to a significantly higher rate of changing routine indicated by support workers

with less experience, less than 17 months (21%) and those with medium experience, 18-48 months (3%), but not for the higher, greater than 48 months (6%), industry experience group.

Predicted Success of Choice Training

There were significant effects of the support workers predicted success of choice training on the frequency of impacts overall, and on the frequency of both *resident impacts*, and *impacts on others* individually (Table 8.31).

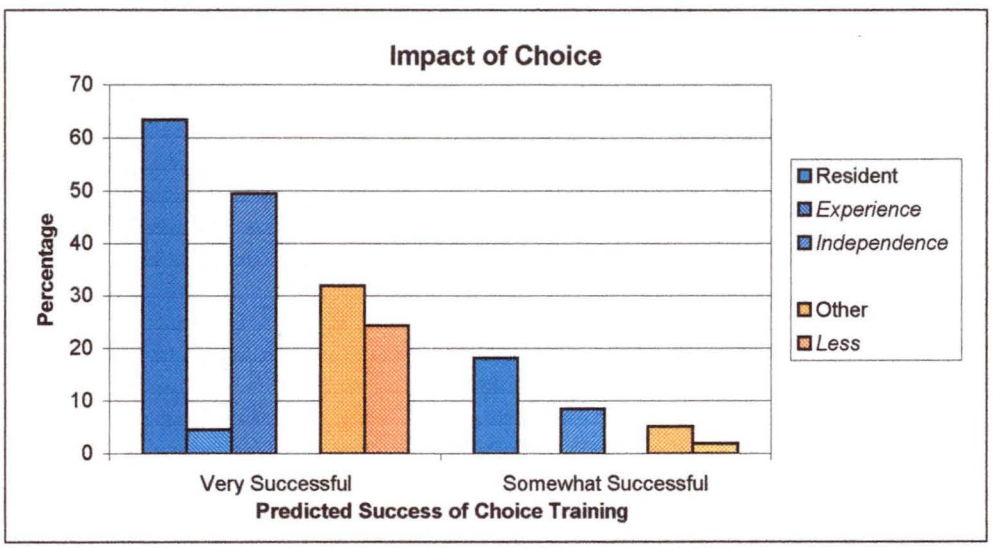

Figure 8.24: Effect of support worker rating of success of choice training on different *impacts of choice.*

The *resident impacts* that were influenced were *new experience* and *greater independence*, while the *other impact* was *less work for support workers*. In each case, the different impacts of choice were rated as greater by support workers who anticipated that the choice training would be very successful, than those who thought the training would be somewhat successful (Figure 8.24).

DISCUSSION

Resident Characteristics

Personal

Neither resident age nor gender proved to be significantly correlated to any of the six aspects of choice examined in this chapter. The lack of an effect of gender was consistent with the findings of an examination of gender in different home environments by Shaddock, Bennett, Dowse, Guggenheimer, Stancliffe and Zilber (1992). However, Shaddock, Zilber, Guggenheimer, Dowse, Bennett and Browne (1993) found that males had significantly more choices than females in a study of day placement settings.

Ability

General ability was measured in three ways: a rating of intellectual disability by house managers, adaptive functioning using the Scales of Independent Behaviour (SIB) assessment completed by residents, and the presence of a physical disability. Level of intellectual disability and physical disability were both negatively correlated with SIB independence groups. Level of intellectual disability and adaptive behaviour appear to be the major resident characteristics in determining many aspects of choice behaviour. It is however, not possible to conclusively determine whether greater choice development is a determinant or a consequence of improved adaptive behaviour as the study was cross sectional and not longitudinal (Stancliffe, 2001)

Communication skills were measured as part of the SIB assessment and also using the Communication Assessment Profile (CASP) which was completed by residents. However the CASP assessment did not significantly correlate with any of the aspects of choice. One of the reasons for this may be that it relies on subjects' ability to recognise and identify pictures and some of the content is UK specific (Balandin, 1991), thus the profile may not give a sufficiently accurate indication of communication skills .

(1) Opportunities for Choice

It was hypothesised that current choice opportunities would decrease with increasing intellectual disability level, and therefore increase with increasing SIB scores.

As predicted, support workers indicated that the majority of residents in this study had opportunities in daily choice-making, but the level was significantly less for those with a severe intellectual disability than those with a mild intellectual disability rating. This is consistent with Stancliffe (1997) who found that level of intellectual disability and adaptive behaviour are related to choice.

Frequency of current opportunities was less for those with lower SIB independence scores than either medium or high SIB independence groups. The smaller number of opportunities for those in the low SIB group, than the other two SIB groups suggests that when a resident achieves a certain skill level, they are able to access choices in daily-living areas.

Although SIB group did not determine the type of opportunity for choice, resident-initiated choice opportunities were more frequent for those in the higher than the lower SIB group. This finding is consistent with greater independence for residents with greater ability.

(2) Choice Presentation

Level of intellectual disability was also related to the type of communication used to present other-initiated choice opportunities. More choices were presented using speech and fewer choices presented using real objects for the mild group, than the severe intellectual disability group.

Similarly, although SIB group did not influence the frequency of other-initiated choice opportunities, it did affect the type of communication used to present the choice opportunity. Residents in the medium and high SIB groups were more likely to have choices presented to them using speech than any other communication form, while those in the low skills group were equally likely to have choices presented using speech or real objects. This resulted in a much higher use of real objects for the low skills group and suggests that real objects may be used in an attempt to

compensate for lower skill levels, or are only resorted to when the more familiar used speech is unsuccessful. Those with milder disabilities and greater skill development may also benefit from the use of real objects to aid understanding.

(3) Limitations on Choice

Although there was no effect of intellectual disability or SIB group on the frequency of limitations on choice generally, there was a trend towards those in the low SIB group having more limitations on their choices due to ability than those in the high SIB group.

(4) Responses to Choice

Although none of the ability measures had an effect on the rate of response to choice opportunities, there were effects of physical disability and SIB independence group on the means used to respond to those opportunities. Those without a physical disability were more likely to respond to choice using action than any other means, while those with a physical disability were equally likely to respond using action, vocalisation or gesture. This led to a greater use of action for those without than with a physical disability, and greater use of gesture for those with than without a physical disability.

Residents in the high SIB group were more likely to respond using action, those in the medium group to use action or vocalisation, and those in the low SIB group to use action, vocalisation, or gesture. This again suggests that the greater the general skill level, the more independent the choice-making.

(5) Follow-Through of Choice

Both intellectual disability and SIB group had an effect on the agent-of-follow-through, but not on the frequency of follow-through generally perhaps due to a ceiling effect with high rates of follow-through reported for all. Those in the severe intellectual disability group however, were less likely to follow-through with choices themselves than the other two groups, and more likely to have another follow-through with the choice for them.

Residents in the medium and high SIB independence groups were also most likely to follow-through with choices themselves, while those in the low group were equally likely to follow-through with the choices themselves alone, with assistance, or for it to be followed through by another. As the residents are just as likely to be independent as not, it is possible that they could become more independent if support workers allowed them.

The lack of difference between mild and moderate disability groups, and the medium and high SIB groups, in frequency of follow-through of the choices by the residents themselves suggests that residents with a wide range of ability are capable of following through with choices alone. Although the skills measured by the SIB scales may not be specifically required to follow-through with the choice, they may contribute to a sense of confidence and capability in the resident, and the appearance of competence to others. It may be these perceptions as much as skill itself that influence whether the *resident* or *another* follows through with the choice.

Resident Choice Experience

Two choice experience characteristics were examined, experience in daily choice-making and experience in major life choices. These were measured in quite different ways but it was expected that experience with daily choice would form a foundation for making choices in major life areas. It would therefore be predicted that the more involved the resident was in major life decisions, the more likely that they would already be independent in daily choice areas.

There appeared to be two basic patterns, which were associated with the experience of the resident. Those residents with more experience in making choices, had more choice opportunities and tended to initiate their own choices. Although choices were more likely to be presented using speech than real objects, they communicated their responses by following through with the choice themselves using action.

(1) Opportunities for Choice

The greater the daily choice experience the more frequent the opportunities for making choices. However, this was only true for resident-initiated choice opportunities with the result that for the high daily choice experience group there were significantly more resident-initiated choice opportunities than other-initiated choice opportunities. As the frequency of other-initiated choice opportunities did not change regardless of experience with daily choice, support workers may not be effectively recognising resident ability and adjusting their intervention accordingly.

(2) Choice Presentation

For those in the low daily choice experience group there was no difference between the frequency of speech and real objects to present choice opportunities, while for the other two groups speech was more likely than real objects. The use of speech to present choice opportunities increased with experience in daily choices while the use of real objects decreased. This may have been due to the correlations between daily choice experience and both intellectual disability and adaptive functioning (SIB).

(4) Responses to Choice

Residents with more daily choice experience are also more likely to respond to choice opportunities using action although the increase in overall response rate with experience in making daily choices did not reach the required level of significance.

(5) Follow-Through of Choice

For those in the low daily choice experience group there was no difference between the frequency of *residents* or *others* following through with choices. The significant increase in *residents*, and decrease in *others* following through with choices with increasing daily choice experience resulted in a significant difference between these two follow-through agents for the high daily choice experience group, and the frequency of *others* following through with choices alone dropping below the frequency of *residents and others* following through with the choices together.

Combined with the increase in resident-initiated choice opportunities, this increase in independent follow-through is consistent with a study which found that teaching choice-making to people with moderate/severe disabilities resulted in more self-initiated and sustained leisure skill participation (Nietupski, Hamre-Nietupski, Green, Varnum-Teeter, Twedt, LePera, Scebold & Hanrahan, 1996). Choice skills enable the individuals to access and participate in activities without needing to wait for others to assist them.

Similarly, the greater the major life choice experience, the more likely that *residents* would follow-through with their choices rather than *others* do it for them. Although it is possible that involvement in follow-through requires major life choice experience, it is more likely that residents only become involved in major life choices when they have well developed skills, and these skills include the ability to follow-through with the choices themselves. However, there was no correlation between daily and major life choice experience.

Residential History

The residential history of the resident is expected to have played a part in exposure to different periods and degrees of normalised environments and thus influenced previous experience of choice-making. Residential history includes whether or not the resident had been institutionalised, for how long, and how long they had been living in their current residence. Residential history may also influence the perceived competence of residents to make choices in the present.

(2) Choice Presentation

The communication form used to present other-initiated choice opportunities was also influenced by the length of time the resident had lived in the house. Speech was more likely, and the use of real objects less likely the longer the resident had resided in the house. It may be that language skills developed after living in the house for a period, or that support workers initially use the more basic and concrete forms of communication until they are able to determine and become familiar with the communication skills of the residents. It is perhaps more likely that

residential placements are more successful, or that residents were deinstitutionalised earlier if they have more developed communication skills. However, there was no correlation between period of residence and any of the measures of ability.

(3) Limitations on Choice

Residents living in the current house for less than 18 months had more resident limitations than environmental limitations. Although this effect was not evident for the other two period-of-residence groups, there was a lot of variation between residents.

In particular, residents who had lived in a residence for a short time had more choices limited by communication skills than those who had lived in their residence for a long time. This is consistent with the finding above regarding the form of communication for choice opportunities but as there was no effect of CASP group or SIB social and communication skills cluster, it may be a difference perceived by the support worker rather than an actual deficit.

(4) Responses to Choice

The response rate to choices tended to be higher for those who had lived in the house for at least 18 months. This was perhaps the result of increased familiarity of support workers with residents resulting in opportunities matching resident's abilities more closely, or support workers recognising the idiosyncratic responses of the residents more frequently. Other possible explanations include that residents became more familiar with their environment and more confident in their ability to follow-through with choices themselves; alternatively, residents with more developed choice skills are more successful in their residential placements or were able to express a preference to move out of the institution earlier.

(6) Impact of Choice

Both period of residence and a history of institutionalisation were significantly related to a lower rate of impact of choice on others. Support workers indicated a higher rate of impact on the resident for those who had not lived in the house very long. The type of resident impact identified

was a change in the resident's routine as a result of the choice event. This suggests that routine is perhaps more stable or rigid and less changeable after a period of residence as there was no difference in the response rates for those residing for different periods of time, and the repercussions of this on opportunities for real choice should be considered.

Impacts on others were less frequent following the choices of residents who had lived in an institution. In particular, support workers were less likely to indicate either a reduction in work or an increase in work as a result of the choices of residents who had lived in an institution. This is perhaps because residents who have been institutionalised have learnt how to make choices that do not impinge on others. Alternatively, the key may be the perception of the support worker, rating more work if they focussed on the short term difficulties, and less work if the focus was on the benefits of greater independence, although this does not explain why these impacts were rated as higher for residents who had not been institutionalised.

Environmental Characteristics

Normalisation

It was hypothesised that those living in houses that were more normalised would have more opportunities for choice, greater support to make them, but would be more independent. However, any differences were likely to be small, as the houses examined did not vary greatly in normalisation score, with the lowest rating of 43 equivalent to 72% of the total possible. Thus it may require a greater range of normalisation scores to fully answer the question regarding the influence of normalisation on choice. Despite this, some positive trends are described below.

(3) Limitations on Choice

More choices of residents living in houses with a medium normalisation rating were considered to be limited than those living in less normalised houses. The relevant limitation was that of ability as those in the medium normalisation group had more limitations on choice due to

ability than either the low or high normalisation groups. Although a difference between the medium and high normalisation groups could have been attributed to the higher independence and motor skills scores for the high normalisation group, there were no differences in ability between the low and medium normalisation groups. This effect may be due to support workers being less aware of limitations rather than there being fewer limitations for the low group, whereas the greater ability for the high group may indicate fewer limitations on choice.

(5) Follow-Through of Choice

Normalisation rating also predicted the frequency of choices followed through with. The choices of residents living in houses with a low normalisation rating were less likely to be followed through. This is consistent with the support workers in houses with higher normalisation ratings being more supportive of resident choice-making.

The degree of normalisation of a household also appears to influence the agent-of-follow-through of choice responses. For residents in the medium normalisation group, there was an equal likelihood that the *resident*, *another*, or both *resident and another* together would follow-through with the choice. This also resulted in a significantly higher rate of *other* follow-through for the medium normalisation group than the other groups. For the other two groups, *residents* were most likely to follow-through with the choices alone. Although this may be a sign of greater independence, it may also be a sign of lack of support, at least for the lower normalisation group, which did not have any greater skill than the medium group.

Temporal Rhythm

It was anticipated that choice would fluctuate depending on the time and day of the choice. This was due to the normal limitations that commitments at different times of the day, and days of the week, can play on choice, such as needing to prepare for work and day placement commitments on weekday mornings. This type of variation is predicted by the principles of normalisation as most people's routines vary at different times and on different days (Briton, 1979). However, there were no effects

of day of the week on any aspect of choice, despite exactly the same choices being examined. This may be the result of similar support worker routines attached to shift times regardless of the day. There were however a couple of effects of time of day although these effects need to be treated with caution as the specific choice questions differed at the two times of day.

(1) Opportunities for Choice

Contrary to the expectation that choice would be more limited in the morning than in the afternoon, choices were more frequent in the morning. It may be that time limitations in the morning mean that residents are required to be more independent and make more choices for themselves, although there were no differences between the frequencies of different types of choice opportunity. Another possibility is that the types of choices that were explored in the afternoon were less familiar to residents or less acceptable to support workers. Perhaps leisure choices are less acceptable than hygiene choices as each of these were only examined at one time of day.

(6) Impact of Choice

There were significantly more resident impacts than impacts on others in both the morning and the afternoon, and more resident impacts in the morning than the afternoon, but no difference between times of day for the frequency of other impacts. This suggests that choice has more of an impact on the residents themselves, particularly in the morning perhaps due to the reduced support available.

Support Worker Characteristics

The age of the support worker, the number of hours they work per week, and the period of experience they have working with the specific group of people with intellectual disabilities did not have any effect on the aspects of choice examined. Nor was their an effect of support worker participation in Technical and Further Education (TAFE) training in disabilities on any aspect of choice behaviour. Cullari and Ferguson

(1981) suggest that the education level of many direct-care staff is not adequate for them to implement programs correctly.

Personal

It was hypothesised that female support workers may look at choices in different ways than males, possibly as a result of the tendency for women to be perceived as the caring sex and the greater likelihood of a history of child rearing.

(3) Limitations on Choice

An interaction between gender and type of limitations appears to have been the result of a trend towards males identifying more resident than environmental limitations, however this did not reach significance.

The only aspect of choice that was affected by gender was the rated frequency of social limitations on choice. In this case, males rated more choices as having limitations due to social constraints. It is possible that males were more influenced by the social implications of social role valorisation, which emphasises avoiding the appearance of differences that may lead to labelling and devaluation.

Familiarity with Residents

Contrary to expectations, support worker experience with the specific resident group whose choice behaviours were being rated, did not appear to influence any aspect of choice. This suggests that support worker attitudes are influenced more by factors other than familiarity with residents.

Industry Experience

There was no effect of time that the support worker had worked in the house on choice behaviours despite this presumably being a measure of familiarity with the particular residents they are currently working with. There was an effect of time in the disability field, which is indicative of general experience, but it was not in the direction expected and was in relation to one particular form of impact of choice only.

(6) Impact of Choice

Although there was no effect of experience in the disability field on the frequency of impacts of choice generally, there was an effect of experience on the frequency of choice changing resident's *routine*. Support workers with less experience indicated that resident's routine changed more often as a result of choice than those with more experience. This effect may have been due to more experienced support workers becoming stale and not challenging routine as frequently as less experienced support workers who may be fresher and more enthusiastic and less likely to make routines rigid.

Job Satisfaction

Job satisfaction was investigated as an influence on choice as it was hypothesised that support worker satisfaction with their job would influence how enthusiastic and motivated they would be in supporting choice. None of the support workers admitted to being dissatisfied with their job so comparisons were made between those who felt satisfied and those who were neutral towards their job.

(2) Choice Presentation

Those who were satisfied with their job were more likely to use speech to communicate an other-initiated choice opportunity than any other communication form. There were no differences between frequencies of different communication forms for those who were neutral about their job.

Choice Knowledge and Attitudes

Previous attendance of support workers at a disability services workshop on choice was measured in order to determine the effectiveness of previous choice training. The only aspect of choice behaviour that was influenced by attendance at one of these workshops was the frequency of opportunities for choice. It thus appears that there is a need for a more effective method to train choice-making behaviours to adults with intellectual disabilities. This approach is limited as the workshops are usually attended only once, they are for support workers only, and they examine general principles not interventions for individual residents.

The support workers' prediction of the success of training was gauged in an attempt to determine the effect of expectations on the way the support worker viewed choice-making, however it only appeared to influence the impact of choice.

(1) Opportunities for Choice

The only area that was influenced by previous support worker attendance at a choice workshop was the frequency of opportunities for choice at baseline. The effect was due to a higher rate of choice opportunity reported by those who had not attended training. Although this appears to be contrary to expectations at first it is possible that one of the key influences of that training was to give support workers a more accurate understanding of what constitutes a real opportunity for choice.

(6) Impact of Choice

The only area that was effected by predicted success of training, was the frequency of several impacts of choice-making. The relevant impacts were increased independence and new experiences for residents, and less work for support workers. All of these impacts were considered more frequent by support workers who anticipated that choice training would be very successful. As all of these impacts are positive, if the support worker can see the value of the training, they may be more likely to predict the success of it, and perhaps even put more effort in and increase the likelihood of the training being successful.

CONCLUSION

The results of this study are summarised in Table 8.32. This table shows that various resident, environment, and support worker characteristics influenced different aspects of choice behaviour although these influences did not always match those predicted.

Table 8.32: Summary of influences of resident, environment, and support worker characteristics on the six aspects of choice behaviour from the Daily Choice Questionnaire.

CHOICE ASPECTS	CHARACTERISTICS									
	Resident				Environment		Support Worker			
	Personal	Ability	Residential history	Choice experience	Normalisation	Temporal rhythm	Personal	Industry experience	Job satisfaction	Success of training
Stage A: OPTION RECOGNITION										
(1) Opportunities for Choice										
No/Yes		ID SIB		daily		day				
Resident-initiated		ID SIB		daily						
Other-initiated										
(2) Choice Presentation										
Speech		ID SIB	time	daily						
Real objects		ID SIB	time	daily major				course		
Gestures										
Stage B: EVALUATION AND SELECTION										
3) Limitations on Choice										
No/Yes		ID SIB			norm	day				
Resident		ID SIB			norm	day				
ability		SIB				day				
communication			period							
Environment										
society							gender			
(4) Responses to Choice										
No/Yes			period	daily	norm	day			satis	
Action		phys SIB		daily	norm	time				
Vocalisation		SIB	period			day	gender			
Gesture		phys					gender			
Stage C: ACTING ON THE SELECTION										
(5) Follow-Through of Choice										
No/Yes				daily	norm	time	gender			
Resident only		ID SIB		daily major	norm	time				
Other only		ID SIB	period	daily major	norm	day				
Resident & Other	age			major					satis	
(6) Impact of Choice										
No/Yes			period instit			day				success
Resident			period			day				success
changed routine			period					industry		
new experience										success
independence										success
Other			instit							success
extra work			instit							
less work			instit							success

cont.

Note: Red $p<0.01$, Black $p<0.05$
Bold – potentially malleable characteristic
Highlight – predicted influences of characteristics on aspects of choice behaviour
ID=intellectual disability, *SIB*=adaptive functioning, *phys*=physical disability, *period*=period of residence, *instit*=history of institutionalisation, *daily*=daily choice experience, *major*=major life choice experience, *norm*=normalisation, *time*=time of day, *day*=day of week, *course*=disability qualification, *industry*=time in industry, *satis*=job satisfaction, *success*=predicted success of training.

Resident Characteristics

Choice appears to be primarily related to the level of ability of the individual making choices. Level of intellectual disability and overall independence rating in the Scales of Independent Behaviour (SIB) were related to opportunity frequency and type, communication form for presentation of options, and agent-of-follow-through.

Daily choice experience also appears to affect many aspects of the current choices of residents, while major life choice experience only had an impact on the agent-of-follow-through of choices. This effect may be either a cause or a consequence of the correlations between daily choice experience and both level of intellectual disability and SIB independence score.

Despite predictions otherwise, the Communication Assessment Profile did not relate to any aspect of choice, however the *social and communication skills* cluster of the SIB assessment did relate to many aspects of choice. There was no real effect of gender or age on any aspect of choice. In addition, although it was expected that physical disability would have an impact on choice, this was only the case for the means of choice response.

Residential history proved to be relevant to the choices of adults with intellectual disability. The briefer the period of residence, the more likely real objects were used to present choice opportunities, the more resident limitations there were, particularly with regard to communication skills, the lower the response rate to choice opportunities, and the more impacts there were on residents, particularly changes in routine. The choices of those who had lived in an institution were less likely to impact on others, perhaps because they have learnt not to rely on others.

Environmental Characteristics

Although the environmental characteristic - normalisation rating was quite high for all houses, the residents in the medium normalisation group appeared to have more ability limitations on their choices, and more assistance to follow-through with them. The similarity between the high and low groups in frequency of limitations and more frequent follow-through of choices may have been due to support workers being less aware of limitations, and less supportive of follow-through of choices as a low normalisation rating was also related to fewer choices followed through with.

Despite predictions that choices would differ with the other environmental characteristic – temporal rhythm, there were no differences between choices on weekdays and weekends. There was however a difference between the frequency of opportunities and impacts of choices at different times of day. This may represent similar daily variation as the general population, an artefact of the types of choices examined, or greater independence in the mornings.

Support Worker Characteristics

Support worker characteristics appeared to be less important than resident characteristics in influencing the aspects of choice examined in this chapter. There were however a number of effects including a trend towards male support workers attributing more limitations on choice to the resident than the environment, less experienced support workers reporting more changes in resident routine as a consequence of choice, greater use of speech than other communication forms to present choice by those who were satisfied with their job, more opportunities for choice reported by those who have previously attended a workshop on resident choice, and more positive impacts of choice on both the resident and others reported by support workers who predicted the success of choice training.

Summary

The results of this chapter show that many of the characteristics which influenced choice are potentially malleable and should thus be taken into account when developing training to improve the choice-making behaviours of adults with intellectual disabilities. In particular, developing the skills involved in adaptive functioning by making residents more independent and increasing choice making experience in daily and major life areas should impact on the frequency of resident-initiated opportunities for choice, and follow-through of choice using action. This is consistent with Stancliffe, Abery and Smith's (2000) conclusion that greater independence is consistent with greater control. Increasing the degree of normalisation of the house, emphasising the independence of residents during times when routine is more restricted, and motivating support workers so see the merit and potential success of choice training should also have positive impacts on resident choice-making.

In planning a training study it will be most important to take resident characteristics and normalisation rating into consideration when assigning residents to groups for the training study to ensure appropriate matching. Differences between training groups will then be attributable to differences in training approaches.